# SUMMARY OF IDENTIFIED SUBJECT AREAS IN THE REPORT "ENDING THE ISOLATION"

## INTRODUCTION

The Working Group on HIV Infection and Mental Health developed a detailed "framework for action" to meet the mental health needs of persons with HIV/AIDS. Ten subject areas of importance were identified and within each area specific recommendations were made.

AREA #1:

1. **Develop and foster a positive social environment, which will support people with HIV disease and those close to them and reduce the stigma that is psychologically damaging.**

   HIV disease is everyone's concern. Education is the key to creating a compassionate response to HIV.

   Examples of work supported by the Department of National Health and Welfare:

   - AIDS in the workplace - a practical approach for employers developed by the Canadian AIDS Society
   - AIDS Sexuality Curriculum Model - a project with Council of Ministers of Education
   - AIDS/HIV National Policy Guidelines for Youth Serving Agencies - involved child welfare and young offender organizations from across Canada

AREA #2:

2. **End the individual isolation that causes distress for all those affected by HIV and empower people to develop and draw on the strengths and support of self-help.**

   Isolation and loneliness are serious problems for persons with HIV disease and their families and caregivers.

   Examples of work supported by the Department of National Health and Welfare:

   - Provincial/Territorial HIV Counselling Workshops - to enhance the HIV/AIDS counselling capacity
   - AIDS Treatment Information Service - a national service under development to provide treatment information to caregivers and HIV positive persons.

AREA #3:

3. **Ensure that all those living with HIV disease have access to financial security as well as the opportunity to participate in activities that give meaning to life.**

.../2

Financial security is an urgent need for people living with HIV. HIV disease has hit hardest the younger gay men (ranging from 20 to 50 years of age) who may not have the insurance, savings or personal safety nets to cope with a long-term, debilitating and expensive illness.

Examples of work supported by the Department National Health and Welfare:

- "Meeting the Income Support Needs of Persons Living with HIV and AIDS" - a project to look at collaborative/ practical options for improving the financial and social security of persons living with AIDS
- "Getting Hooked Up" - a project to look at how the social service delivery/access connection works for people with HIV/AIDS

AREA #4:

4. **Improve the availability and quality of counselling services. At the same time, ensure that all those providing HIV counselling services have the training and support they need to help their clients develop coping skills and to safeguard their own mental health.**

Canadians need an on-going range of counselling and support services. In addition to helping people come to terms with death, counsellors must help people come to terms with living with this illness and focus on health promotion.

Examples of work supported by the Department of National Health and Welfare:

- HIV Counselling Model developed with Canadian Hemophilia Society
- HIV Counselling Guidelines produced by the Canadian Medical Association
- "Caring Together" - an integrated model of care for persons living with AIDS
- Stress Management Module for HIV/AIDS caregivers developed by the Canadian Hospital Association
- Provincial/Territorial HIV Counselling Workshops - to expand the network of counsellors dealing with specific areas of counselling.

AREA #5:

5. **Ensure that people with HIV have access to optimal clinical management and services and to information about those services.**

.../3

Access to medical services, drugs, treatment and information plays an important role in an individual's mental health and his/her ability to cope with the stresses associated with HIV.

Examples of work supported by the Department of National Health and Welfare:

- AIDS Treatment Information Service - to provide treatment information to caregivers and HIV positive persons
- Home Support Canada Training Package - a project to enhance training of home support workers providing service to HIV/AIDS persons
- Video Series on AIDS - to provide information on essential care, treatment and support for family physicians and other health care workers caring for persons living with AIDS
- College of Family Physicians' Education and Information Campaign

AREA #6:

6. **Ensure that caregivers, partners, families, friends and individuals with HIV are aware of the signs, symptoms and demands of AIDS dementia and have the support and resources to provide care for the growing number of individuals who will develop AIDS dementia.**

More knowledge about AIDS dementia is necessary to enhance HIV care and treatment.

Examples of work supported by the Department of National Health and Welfare:

- AIDS Treatment Information Service - will include treatment information on AIDS dementia as a resource for caregivers and HIV positive persons
- College of Family Physicians Education and Information Campaign
- Video Series on AIDS - to provide information on essential care, treatment and support for family physicians and other health care workers caring for persons living with AIDS
- HIV Educational Package for Nurses - developed by the Canadian Nurses Association

AREA #7:

7. **Encourage a comprehensive, cooperative, community-based support system, which will enhance the capacity of everyone involved to provide psychosocial services for those living with HIV and their partners, families, friends and caregivers.**

.../4

As HIV has become a more manageable long term illness, the focus of care has shifted from hospitals to the community.

Examples of work supported by the Department of National Health and Welfare:

- "Caring Together" in Alberta and "Project Access" in Quebec - two pilot projects to develop a model of integrated care delivery
- Home Support Canada Training Package - to enhance support services delivered to persons at home
- "Train the Trainers" - a training package for family service counsellors developed by Family Service Canada

AREA #8:

8. **Reinforce and build the strengths of community-based HIV-related organizations.**

AIDS organizations have successfully developed innovative mental health programs and services.

- AIDS Community Action Program - supports the infrastructure of community-based AIDS organizations nationally
- HIV Blood Transfusion Group - Outreach and Support Service for persons infected through blood transfusion.

AREA #9:

9. **Ensure that HIV mental health programs and services are sensitive to the special needs of particular groups or communities affected by HIV.**

Programs, services and materials developed and provided should reflect the diverse needs of all individuals and groups affected by HIV, such as aboriginals, individuals with hemophilia, HIV infected women, youth, ethnocultural communities, individuals with disabilities and individuals in prison.

Examples of work supported by the Department of Health and Welfare:

- Ontario Council of Agencies Serving Immigrants held educational forum/action strategies for immigrant groups to respond to HIV/AIDS
- AIDS Prevention Programs for Injection Drug Users projects - multifaceted designed to prevent the spread of HIV infection among injection drug users
- Joint National Committee on Aboriginal AIDS Education and Prevention

.../5

- Resource Package for Ethnocultural Media
- Women and AIDS Education and Prevention - Planned Parenthood Federation of Canada

AREA #10:

10. **Ensure research is undertaken on effective HIV mental health services and ensure that research data are available and used to plan effective HIV-related mental health services for the second decade.**

Mental health related research has to reflect the needs of those most affected by HIV, be practical, and provide information that will be accessible and used.

Examples of work supported by the Department of Health and Welfare:

- "Stress Management Approaches for Persons Living with HIV" developed by Toronto General Hospital
- "Housing for Persons With HIV Infection in Canada: Issues and Recommendations" - in collaboration with the University of British Columbia's Centre for Human Settlements
- Study of Income Issues Related to HIV/AIDS - two workshops are planned to bring together AIDS community groups and Income Security Representatives

Health and Welfare Canada
Santé et Bien-être social Canada

# Ending the Isolation

## HIV Disease and Mental Health in the Second Decade

Canada

# Ending the Isolation

## HIV Disease and Mental Health in the Second Decade

Published by the authority of the Minister of National Health and Welfare

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# Report of the Federal Centre for AIDS Working Group on HIV Infection and Mental Health

**Presented to**
**Health and Welfare Canada**
**November 1991**

# Ending the Isolation:
# HIV and Mental Health in the Second Decade

**is dedicated to**
**the thousands of Canadians**
**who have died of HIV disease**

**and to the memory of**
**Mr. Don Munro**
**former member of the working group**
**and**
**Ms. Thelma Law**
**former secretary to the working group**

# Preface

***Mental health is the capacity of the individual, the group and the environment to interact with one another in ways that promote subjective well-being, the optimal development and use of mental abilities (cognitive, affective and relational), the achievement of individuals and collective goals consistent with justice and the attainment and preservation of conditions of fundamental equality.***

***Mental Health for Canadians: Striking A Balance***
***Health and Welfare Canada, 1988.***

The Federal Centre for AIDS Working Group on HIV Infection and Mental Health began work in December 1988. Its purpose was to evaluate the state of mental health service delivery as it responds to those who have HIV infection, and to those who have been affected by this epidemic, and make program recommendations to the Federal Centre for AIDS .

Its objectives were to:

- Identify all components of care and care delivery.
- Identify gaps in service, education and support programs.
- Propose ways of co-ordinating these programs as needed.
- Define the roles of health and social care workers meeting the needs of those affected by the psychosocial and neuropsychiatric aspects of HIV infection.
- Suggest research priorities to ensure ongoing consideration of HIV infection and mental health.

To do this, the group chose to listen. Listen to those living with HIV. Listen to their partners, families and friends. Listen to the caregivers. From people on the front lines — both infected and affected — the group would learn first hand about the mental health problems — the shortages, the gaps in services and education, and the misunderstandings. The group also hoped to learn about the services and skills that have helped Canadians cope. From this they would develop innovative solutions that individuals, organizations, professions, institutions, communities and governments could use to meet the mental health needs of those affected by HIV. Over a period of two and a half years, the Working Group on HIV Infection and Mental Health heard from as many people across Canada as possible. Members organized three different opportunities for individuals and organizations to give their ideas and advice:

1. **A National Needs Assessment —** Detailed questionnaires — for people with HIV, family members and significant others, and caregivers — were distributed to 124 key service providers and 26 organizations that are members of the Canadian AIDS Society (CAS). One thousand two hundred and sixty-two individuals — 581 people with HIV, 459 caregivers and 222 friends and family members — responded. In addition to answering the questions, participants were invited to add their comments and suggestions. A summary of the needs assessment is included in Appendix I.
2. **National Hearings** — held in Halifax, Montreal, Toronto and Vancouver. Five hundred and fifteen individuals and groups were contacted and invited to submit written briefs. The working group received 52 written submissions from 106 groups. From these submissions, 45 groups were selected to make oral

*Only by listening and working together as a caring community can we take the necessary steps to meet the mental health needs of people with HIV, their partners, families and friends, and their caregivers.*

presentations at the hearings. The briefs and transcripts of the hearings are on file at Health and Welfare Canada. A summary is included in Appendix II.

3. **Caring Together / Entraide** — two conferences for caregivers, held in Calgary and Ottawa. Over 800 caregivers — formal and informal, paid and unpaid — from every province and territory in Canada and every type of care setting attended. Copies of the conference report are available on request, and a summary is included in Appendix III.

Having listened closely to the life stories of people with HIV disease, we are able to describe the mental health problems of Canadians who are not only living with a fatal disease, but without the comfort society usually gives to those who are ill. Individuals living with human immunodeficiency virus (HIV) and those who have developed acquired immune deficiency syndrome (AIDS) have serious and immediate mental health needs. Their anxiety, loss, pain, anger, frustration and hope are real. Not only do they have physical problems, they have unmet spiritual and social needs that threaten their mental health.

All are facing the challenge of living with a communicable illness for which there is, as yet, no cure. Those who are infected but have no symptoms need ongoing social support, counselling and education to help them maintain their quality of life and mental health while living with HIV. They also need vocational and recreational opportunities. Some, faced with a debilitating chronic illness, need assistance with income, housing and legal issues. Some suffer from AIDS dementia caused by the virus and need intensive care.

Mental health problems related to HIV are not confined to those who are infected. The pain and anguish goes further. Partners, families and friends — individuals who are close to someone who is infected and who may also be providing ongoing care — need spiritual and psychosocial support. The small group of caregivers — physicians, nurses, psychiatrists, psychologists, social workers, counsellors, buddies and others who provide medical and social services for people living with HIV — are also feeling the stresses of this illness. For many, their capacity to cope is seriously threatened.

Although some people living with HIV have turned to the formal mental health system for services, more have looked for psychosocial care and support to a growing number of community-based organizations, gay organizations, self-help groups, buddies and volunteers. Although this informal network of service providers has struggled valiantly to meet the mental health needs associated with HIV and has developed some excellent and innovative programs and services, more must be done. Even after almost 10 years of living with this disease, many of the psychosocial needs remain unmet. People living with HIV, their partners, families and caregivers told us there are still too few caregivers and not enough resources. People infected and affected by HIV need more counselling and support services, more information and better medical care. After the first decade, people affected by HIV are still extremely isolated in their fight against this disease.

Members of the working group listened carefully and, based on what they heard, offer the following report. It is our hope that the suggestions and ideas in

***To safeguard and restore the mental health of people affected by HIV is an individual, collective and social responsibility. For those who are infected and affected by HIV, struggling to find meaning and to live well and fully causes great stress. Our society can help ease that anxiety through mutual aid, compassion, solidarity, a willingness to help, and our individual and collective strength.***

these pages will support and encourage the kind of social environment, organizations, structures and working relationships that will end the isolation and meet the mental health needs of Canadians in the second decade of HIV disease.

This report is divided into five sections:

**Part I — Background** provides some basic definitions of HIV disease and mental health.

**Part II — The Impact of HIV Disease on Mental Health** describes in more detail the societal, psychosocial, spiritual, psychological and psychiatric impact of HIV on individuals who are infected and their partners, families and friends.

**Part III — The Impact of HIV Disease on Mental Health Services** describes briefly the mental health-related services that currently exist, the ways caregivers have responded to help individuals cope with HIV, and the psychosocial stress that the caregivers themselves are experiencing.

**Part IV — Needs, Barriers and Coping Skills** describes the general needs of all those affected by HIV, plus the more specific needs of members of certain populations, communities and groups.

**Part V — Ending the Isolation** includes the working group's analysis of the mental health needs in the second decade of HIV, describes a framework for a community-wide response and makes recommendations to the Federal Centre for AIDS.

Our task was to advise the Federal Centre for AIDS. Through the course of our work, it became increasingly clear that the federal government alone cannot solve the serious and urgent problems that prevent people living with HIV, their partners, families, friends and caregivers from receiving the mental health services they need. Ending the isolation will require commitment and action by all levels of government, the formal mental health system and the informal HIV-related network of services. Although we make strong recommendations to the federal government to act, we also suggest roles that others can and should play. Only by listening and working together as a caring community can we take the steps so urgently needed to meet the mental health needs of people with HIV, their partners, families and friends, and their caregivers.

The Federal Centre for AIDS Working Group on HIV Infection and Mental Health would like to thank all those who participated in this process and helped in our deliberations. Their needs, thoughts and ideas form the basis for this document and their words are reflected on every page. We would also like to encourage those who did not participate to speak out and be heard. Because of the isolation that surrounds HIV disease, many are still silent. The working group hopes that this report will be a bridge or a beginning.

Stephen Woo

**Stephen Woo**
**Chair - Federal Centre for AIDS**
**Working Group on HIV Infection and Mental Health**

## The Federal Centre for AIDS
## Working Group on HIV Infection and Mental Health

The members of the working group came from across Canada and represented a variety of experience with HIV disease and mental health. They respectfully submit this report to the Federal Centre for AIDS, Health and Welfare Canada.

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## Acknowledgements

The FCA Working Group on HIV Infection and Mental Health gratefully acknowledges the contributions made by individuals who were not members including:

- All the people living with HIV disease, their partners, families, friends and caregivers who submitted briefs, made presentations, spoke to the working group and participated in the needs assessment
- Dr. Margaret Somerville, legal consultant
- Dr. Donna Lamping and her team at McGill University who assisted with the needs assessment
- Ms. Debbie Bang and her team at the University of Toronto who assisted with the hearings
- Mr. Ron Harris, an original member of the working group
- Mrs. Anne Queenan who provided administrative support to the working group
- Mrs. Jean Bacon who edited the final report
- The Department of Psychiatry, Mount Sinai Hospital, Toronto

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# Ending the Isolation: HIV Disease and Mental Health in the Second Decade

## Executive Summary

In December 1988, the Federal Centre for AIDS established its Working Group on HIV Infection and Mental Health. Fifteen individuals from different parts of Canada and with a variety of experience with HIV infection and mental health came together to examine the mental health needs associated with HIV disease and the services available. Their task was to recommend ways to solve problems and improve the mental health services available to all those affected by HIV.

To do this, the group conducted a national needs assessment, held hearings across the country and organized a conference for caregivers. Through these forums, members were able to hear from those living with HIV and their partners, families, friends and caregivers.

Having listened closely to the life stories of people affected by HIV disease, the working group is able to describe the mental health problems of Canadians who are living with a fatal disease, and without the comfort society usually gives to those who are ill. Not only do they have physical problems that threaten their mental health, they have psychological, spiritual, socio-cultural and socio-economic needs.

The report describes:

- the changing nature of HIV disease and mental health
- the impact of HIV disease on mental health
- the impact of HIV disease on mental health services
- mental health needs, barriers to needed services and coping skills

From the information the working group heard and collected, it is clear that — although progress has been made — after almost 10 years of living with this disease, many of the mental health needs associated with HIV disease remain unmet. People living with HIV disease and their partners, families and caregivers told the working group that there are still too few caregivers and not enough resources, and that they need:

- financial assistance
- professional counselling
- peer support
- information
- medical care

Looking beyond these specific needs to the problems and barriers people with HIV face when seeking mental health services, the working group made several key observations.

- More devastating than the virus itself in terms of mental health is the psychosocial environment — **the secrecy, stigma, religious taboos, homophobia and discrimination** — in which those with HIV, their partners, families and caregivers live each day.
- The secrecy and stigma that surrounds HIV isolates people affected by HIV from the rest of society and from one another, robbing them of the community support and compassion that will help them cope.
- Individuals in small, remote communities also face the extra stress of **geographic isolation**. They often lack medical as well as psychosocial support and need some kind of lifeline to connect them to services.
- HIV disease has hit hardest among younger Canadians (20 to 50 years of age), who may not have the insurance, savings or personal safety nets to cope with a long-term, debilitating and expensive illness. Unfortunately most of Canada's **social support programs are not flexible enough** to meet the practical, financial needs of people with HIV.
- In the early days of AIDS, the time between diagnosis and death was very short. However, with early diagnosis and new treatments, Canadians with HIV disease must now learn to **live with HIV**, and they need ongoing psychosocial support and a range of counselling and support services.
- Lack of knowledge about **AIDS dementia** is preventing many people with HIV from getting the care they need, and the failure to recognize or treat AIDS dementia is increasing the stress on family, friends and caregivers.
- HIV disease continues to highlight dramatically the gaps, problems and weaknesses in our health care and social service systems. Among individuals and groups involved with HIV disease, there is a surprising **lack of knowledge of the resources** available. The **lack of co-ordination** or networking among groups is further complicated by the issue of territoriality or "ownership of HIV." This threatens the ability of various organizations to work together and to make the most effective use of limited resources.
- Existing health care approaches, programs and delivery systems are inappropriate for many of the individuals and populations affected by HIV disease. **Innovative approaches** for education, social and health services are needed to reach these groups.
- Canadians have been confronted with HIV disease — a new health problem — at a time of **severe financial constraint**.

- More research is required in **evaluating models of care, programs, services and interventions**. Those which are effective can then be implemented in other parts of the country.

In summary, in the second decade it will not simply be a case of providing more services. More services will not help if people must still seek these services in an atmosphere of secrecy and shame. Instead, all of us — individuals, organizations, institutions, communities and governments — must work to create a compassionate social environment. The mental health challenge in the second decade will be ending the isolation and breaking down the social, cultural, economic, psychological, organizational and structural barriers that keep people affected by HIV from openly seeking and receiving the care, comfort and services they need.

To that end, the Working Group on HIV Infection and Mental Health proposes a co-ordinated framework for action for HIV disease and mental health in the second decade which will ensure that:

> **People living with HIV, like other Canadians facing a similarly debilitating, life-threatening condition, have access to compassionate and responsive mental health services which recognize the complexities associated with HIV. The partners, families, friends and caregivers of people with HIV and others affected by the illness should also have access to psychosocial support and services.**

The framework is built on and nurtures the three major sources of strength and innovation developed during the first decade of HIV disease:

- **the courage and support provided by self-help groups**
- **the commitment of people in community-based organizations**
- **the dedication of professional caregivers**

In the view of the working group, to meet the urgent mental health needs of those affected by HIV disease, the following steps must be taken:

1. Develop and foster a positive social environment, which will support people with HIV disease and those close to them and reduce the stigma that is psychologically damaging.
2. End the individual isolation that causes distress for all those affected by HIV and encourage people to develop and draw on the strengths and support of self-help.
3. Ensure that all those living with HIV disease have access to financial security as well as the opportunity to participate in activities that give meaning to life.
4. Improve the availability and quality of counselling services. At the same time, ensure that all those providing HIV counselling services have the training and support they need to help their clients develop coping skills and to safeguard their own mental health.
5. Ensure that people with HIV have access to optimal clinical management and services and to information about those services.

6. Ensure that caregivers, partners, families, friends and individuals with HIV are aware of the signs, symptoms and demands of AIDS dementia and have the support and resources to provide care for the growing number of individuals who will develop AIDS dementia.
7. Encourage a comprehensive, co-operative, community-based support system, which will enhance the capacity of everyone involved to provide psychosocial services for those living with HIV and their partners, families, friends and caregivers.
8. Reinforce and build on the strengths of community-based HIV-related organizations.
9. Ensure that HIV mental health programs and services are sensitive to the special needs of particular groups or communities affected by HIV.
10. Ensure research is undertaken on effective HIV mental health services and ensure that research data is available and used to plan effective HIV-related mental health services for the second decade.

***Ending the Isolation: HIV Disease and Mental Health in the Second Decade*** provides a framework and a call for action for the next decade. The report lists detailed strategies that individuals, organizations, institutions and governments can use, and it describes possible roles for all those who must be involved to end the isolation.

The working group strongly recommends that:

**the federal Department of National Health and Welfare recognize the urgent need to act to safeguard the mental health of those affected by HIV;**

**the federal Department of National Health and Welfare work with other federal agencies, with each province and territory, with professional organizations, with non-governmental organizations and with the private sector to end the isolation and create a concrete plan for community-wide action to end the isolation and meet the mental health needs of those affected by HIV disease; and**

**the federal Department of National Health and Welfare establish an internal, inter-branch group to monitor the implementation of the strategies suggested in this report.**

HIV disease affects us all. We are all held hostage by the virus: some by infection; others by the fear and attitudes which keep us from reaching out.

Because those who are affected have told their stories, because they have been willing to collaborate, because many have already died, we dare to believe in the force of a mutual aid collective. We wish to salute the men and women whose courage to love, to speak out, to lose and to die have finally pushed us out of our individual indifference into the social battle to end the isolation of HIV disease.

# I Background

*"Don't tell us we are going to die. Encourage us to live ..."*

## The changing nature of HIV infection and AIDS

HIV disease and its most severe manifestation, acquired immunodeficiency syndrome (AIDS), is caused by the human immunodeficiency virus (HIV). The virus attacks the immune system, making those infected vulnerable to a range of opportunistic infections. HIV can also attack the neurological system, causing AIDS-related dementia.

The virus, which is carried in blood and other body fluids (semen, vaginal fluids and breastmilk), is transmitted during unprotected, penetrative sexual intercourse and by sharing needles to inject drugs. The virus can also be passed from a woman to a child in the womb or through breastfeeding. Before 1985, when the blood supply began to be screened for HIV, the virus was also transmitted through transfusions of infected blood or blood products. There is also a very small risk of occupational transmission (primarily needlestick injuries) among health care workers who handle blood and bloody body fluids. Because AIDS was a newly identified disease and it took several years to identify the virus and the modes of transmission, it created great anxiety and fear of contagion among those infected, those close to them and health care workers.

In North America, the full-blown syndrome (AIDS) was first diagnosed in 1981 in gay men and then in individuals with hemophilia who received infected blood products. Since then, it has spread among injection drug users who share needles and heterosexuals who are engaged in high risk behaviours.

In the early 1980s, the prognosis for those with HIV disease was poor. In most cases, the infection was not diagnosed until serious disease had already developed, and most people died within a year of diagnosis. Many died of diseases such as pneumonia. Few lived long enough to develop the AIDS-related dementia which has since become an increasingly common manifestation of HIV disease.

Since 1985, the nature and course of HIV disease has changed. With testing, many individuals are being diagnosed while they are still well. Nowadays, many people with HIV disease can maintain their health and live 10 years or longer with the illness. For most of that time, they will be well and free of clinical symptoms, but still coping — psychologically and socially — with a communicable disease that remains potentially life-threatening.

Even for those who become ill, the prognosis is much better. With available treatments, many will find the illnesses more manageable. They will likely require less hospitalization and will, instead, seek treatment and support in the community. They will continue to work and be active socially. Thousands of Canadians are confronted with the challenge of living, knowing they are infected, and trying, by every means available, to slow the progress of the disease and have meaning in their lives.

However, some also face the prospect of being seriously ill for prolonged periods of time. If they become unable to work and support themselves, they may face financial hardships. Many will avoid the physical manifestations heretofore associated with HIV (such as pneumonia) and live longer only to succumb to

*"It is extremely important that the health care system and the community act urgently to help people with HIV disease maintain their mental health."*

more difficult treatable opportunistic infections, such as cytomegalovirus, or AIDS dementia.

Changes in the diagnosis, treatment and progression of HIV have also changed the impact of the illness and the needs it creates. With the medical advances in managing HIV, many people no longer see HIV as a death sentence; they have hope for their future.

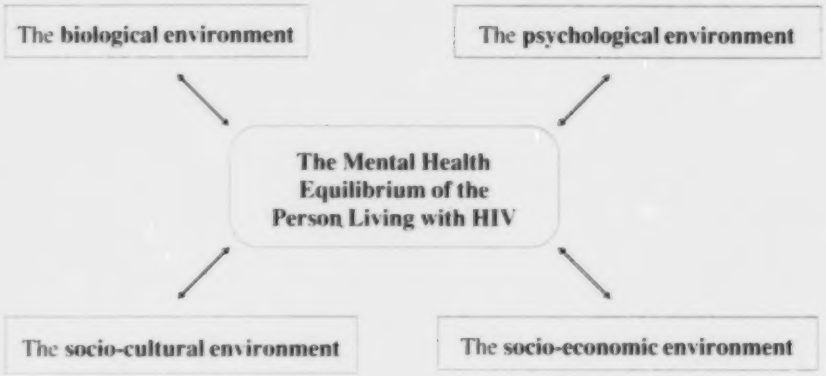
## HIV disease and mental health

> **Good mental health is a sense of balance or equilibrium that allows the individual to realize and use his or her creative potential, to enter into meaningful relationships with others and to participate in the community. A major aspect of mental health is the ability of the individual to cope with the stresses in his or her environment.**

Knowing or believing that you are infected with HIV causes great stress and upsets that balance. For someone with HIV disease, any loss of mental health can be particularly damaging because of the close relationship between the emotions and immune system. A growing body of research into the functioning of the immune system strongly suggests that, through hormonal and autoregulatory mechanisms, reactions to stress and intense feelings of distress have a direct effect on health and on the development of viral attacks and tumors. The cellular system, the part of the immune system most vulnerable to HIV, is particularly sensitive to these regulatory mechanisms. Given the link between stress, its psychological impact (depression), immune response and viral progression, an individual's psychosocial health directly affects his or her capacity to check or slow the progress of HIV disease. **For these reasons, it is extremely important that the health care system and the community act urgently to help people with HIV disease maintain their mental health.**

The individual's ability to cope with the stress of HIV disease and maintain his or her balance and mental health is strongly influenced by the environment which can be divided into four realms as illustrated and defined on the next page.

**In the view of the working group, the purpose of mental health services is to support the person who has HIV in achieving again — and maintaining — the equilibrium that was likely lost with the news of the HIV diagnosis.** The goal of psychosocial support and services is to have a positive impact on each of these four environments or realms. For example, a social worker might provide counselling that would help the individual deal with some of the psychological pressures and also help a person find appropriate, affordable housing which would reduce the anxiety created by socio-economic factors. Psychosocial support is, in effect, a way of affecting the environment and enabling the individual to be healthy, without denying the reality of HIV disease.


The biological environment
The psychological environment
The Mental Health Equilibrium of the Person Living with HIV
The socio-cultural environment
The socio-economic environment

The **psychological environment** includes the individual's mental state and ability to cope with stress and anxiety before diagnosis, his or her system of spiritual beliefs and personal values, and the degree of support the person needs and seeks. Can the person ask for help? Will he or she seek out needed support? Does the individual feel as though he or she has control over medical care? Does the person have enough information to make decisions about medical care?

The **biological environment** includes the individual's general state of health before being diagnosed with HIV, the progression of the infection and the treatment. Does he or she have a history of illness or genetic factors that might make the individual more vulnerable to HIV progression or other disabilities? How uncertain is the prognosis? How is the person responding to treatment? Has the virus started to attack the neurological system? Is it causing neuropsychiatric symptoms?

The **socio-economic environment** includes the person's economic situation before diagnosis, his or her ability to maintain a certain standard of living after and the basic needs that must be met before someone can achieve good health: housing, financial security and meaningful activity. Does the individual have adequate and appropriate housing? Does he or she have a steady source of income? Does the individual have the opportunity to continue to contribute to society in some meaningful way?

The **socio-cultural environment** includes the way society reacts to the individual — both before and after diagnosis — the values and belief systems of the community to which the individual belongs, and the services and supports available. Are those values and beliefs supportive or are they isolating? Will the person suffer discrimination, be stigmatized or be rejected? Are the whole range of services the person will need — support, counselling, drugs, home care, hospice, palliative care — available? Are the counsellors and care providers trained, sensitive, supportive and able to meet the person's needs? Or does the process of seeking care or travelling to receive treatment create more stress?

# II The Impact of HIV on Mental Health

As of August 6, 1991, a total of 5 246 Canadians (5 184 adults and 62 children) had been reported with AIDS. However, it is estimated that up to 50 000 Canadians are infected with HIV but have not developed AIDS. In those infected, the virus can cause serious social, spiritual, psychological and neuropsychiatric damage and have a severe impact on mental health. The mental health of partners, family members and friends may also suffer because of psychological, spiritual and social problems. This chapter describes the social, spiritual, psychological and neuropsychiatric impact of HIV on mental health.

## The Societal Impact of HIV

### Social stigma and discrimination

*"The virus does not simply affect people who are infected, their partners, families and caregivers. It also affects our society and communities. The reaction of society, in turn, affects the mental health of those who are living with HIV."*

*"We continue to work in an environment which still strongly stigmatizes people with HIV infection and, rather less strongly, people who are involved with AIDS care and education. Unhappily, AIDS and HIV disease are still so strongly bound together with gay issues that the public at large cannot separate the two strands."*

*"Personally I was never allowed to discuss this problem with anyone for fear of discrimination and humiliation. My husband was so ashamed when he tested positive. It has been tough for the past five years but we are relieved to hear that people are starting to care and be more empathetic. Please keep caring!"*

In Canada and North America, HIV disease has primarily affected gay men and injection drug users. Canadian society has tended to focus the danger of infection on the individual who is infected rather than on the virus and the methods of transmission. According to this view, it is not unprotected sexual intercourse or sharing needles that is dangerous, but the people — gay men and injection drug users — who carry the virus. Negative attitudes towards homosexuality persist. For example, in the Canada Youth and AIDS survey of 36 000 young Canadians, 50 percent of male adolescents felt that homosexuality was wrong. Fear of HIV may have intensified the latent homophobia in society.

In spite of the fact that most Canadians recognize that people with HIV disease have the right to live without discrimination, incidents of intolerance, discriminiation and violence occur often. In one Atlantic province, a study of infected individuals documented that 17 percent had been victims of intolerance and 7 percent of violence, while 33 percent feared that people around them would reject them. Individuals who, because of their sexual orientation or drug use, were already marginalized have become more so.

Because HIV is a sexually transmitted disease, people who are infected often fear that their private lives will be scrutinized and their morals and behaviour questioned. This stigma often keeps people who are infected from getting help and isolates them from their communities and from one another. For example, many heterosexual men and women and some gay men will not use community-based HIV or AIDS self-help organizations. They fear being openly identified with HIV disease or the gay community. They are then unable to draw on the strength of common experience and understanding for support.

Stigmatization is a major concern among people in smaller or rural communities, where it is difficult to maintain confidentiality and escape society's prejudices. In addition, there are few others who are infected to turn to for support.

One measure of an advanced society is the way it treats members who are sick or disabled. Canadian society usually offers special care, comfort and support to people who are ill. However, with HIV, that care and compassion has often been

*"The stigmatization we go through around the gay question is a big, big problem. It's a particular problem in the rural community."*

withdrawn. Some people talk about those who deserve the virus and those who do not. The stigmatization may affect caregivers who may have to deal with feelings of homophobia as well as their fear of the extremely small but real risk of occupational exposure to HIV. Their own anxiety may lead, in turn, to a lack of compassionate care, comfort and support.

The social climate does not provide the support needed by people who are infected and those close to them. Part of the social reaction is fear of the unknown. Many people are not knowledgeable about homosexuality, sexuality or HIV. Education is needed to reduce the homophobia that is prevalent in Canadian society.

Research has shown that individuals living with HIV and their partners, families and friends are effective educators, spokespeople and advocates and can have the greatest positive impact on public attitudes.

For example, a recent study showed that people who know someone who is infected or who have a gay man or lesbian as a friend, have more positive, supportive attitudes than other adults. In an Ontario study on youth and HIV, the young people surveyed indicated that they were more likely to change their attitudes or behaviour — and sustain that change — after hearing a presentation by someone with HIV.

Gay men and lesbian women who hold responsible, respected positions in society and who are open about their sexuality can be positive role models for society and help dispel some of the misconceptions and stereotypes about homosexuality. Some community-based health and social service organizations and other institutions are actively recruiting gay men and lesbian women onto their boards and into staff positions to help encourage greater understanding and acceptance.

The need for education to reduce the stigma associated with HIV is so great that all levels of government, public health agencies and community organizations should attempt to build partnerships with the private sector and look for opportunities to work together to promote a positive social response to HIV. Corporate sponsorships of HIV fund-raising events or of materials produced for AIDS Awareness Week, for example, communicate to the public a sense of concern, compassion and acceptance for those with HIV disease.

*"Teens are seeing more affirming images of gay men — leaders in the AIDS movement, doctors, researchers, etc. At the same time, they're getting a pretty tough message around their own sexuality and the risk involved in being gay. I think that makes it a hell of a lot tougher for [gay] teens."*

## Impact on sexuality and attitudes towards sexuality

HIV is also having a serious, long-term impact on society's attitudes towards sexuality. Public education messages designed to modify behaviours to prevent the spread of HIV may inadvertently contain a second message: sex is dangerous and sexual partners could be a source of infection and, as such, should be feared.

Although it has not yet been well documented, both gay men and adolescents who are becoming aware of their sexuality may develop a fear of sex and a distrust of partners that may threaten their ability to develop healthy sexuality and sustain intimate relationships.

### Generalized anxiety or the "worried well"

Society's fear of HIV is also causing a generalized anxiety within our communities. Many people, often known as the "worried well," have become convinced they have HIV disease. Some call doctors and hotlines with an often unreasonable fear about the risk of infection. In a small number of people, these fears can, in turn, cause symptoms of severe anxiety or even symptoms similar to those of HIV disease.

The impact of this phenomenon is badly understood. However, the Ontario Ministry of Health AIDS hotline estimates that almost 60 percent of callers are in a state of anxiety that is out of proportion to their personal risk. The majority of these individuals can be reassured by their physicians or by a negative test result. However, some who have pre-existing psychiatric conditions may return repeatedly, creating a heavy workload for doctors and hotline and counselling services. These individuals need to be recognized, adequately assessed and referred to appropriate formal mental health services.

## The Psychosocial Impact of HIV on People with HIV Disease

*"It is not easy being 28 and praying to God you will live to be 35. I wish I didn't have to keep this a secret, go through this basically alone. I wish I could tell my family without fear of rejection. Life isn't easy."*

Individuals with HIV disease must face all the stresses associated with chronic and life-threatening illnesses, including concerns about their future, longevity and quality of life. As with any life-threatening disease, the individual will be coping with loss: the loss of a future, bodily comfort and customary social roles and activities.

In addition, someone with HIV disease may have to adjust to a new physical or social environment. He or she may become preoccupied with mortality, have a heightened sense of personal vulnerability and experience anticipatory grief reactions.

However, because of the nature of the illness — the uncertainty that surrounds the disease (i.e., long incubation period, lack of established means of prevention or cure), the high mortality rate, and the fact that HIV is a sexually transmitted disease — HIV causes more psychosocial distress than other life-threatening illnesses. Because of the social stigma associated with HIV, infected individuals are often denied the comfort and support society otherwise gives to those who are seriously ill. The extreme stress of HIV disease

### About the People Living with HIV Who Completed the Needs Assessment

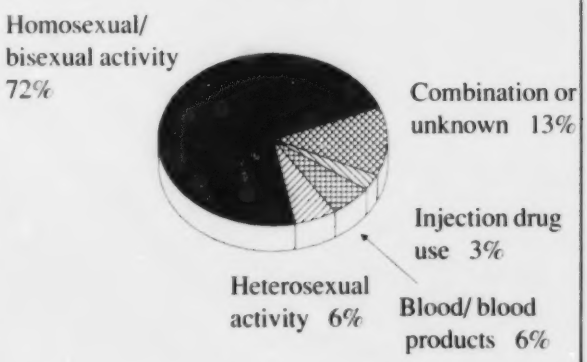
A total of 581 people living with HIV (94% male, 6% female) participated in the needs assessment. In terms of sex, age and mode of infection, they reflected the general characteristics of the Canadians who have been reported with AIDS.

Recruited through health care providers and AIDS organizations, all had made contact with the formal and informal HIV care systems and were receiving services.

Most were:

- white (87%)
- English-speaking (84%)
- born in Canada (85%)
- highly educated (67% with at least some post-secondary education)
- living in their own homes (78%) in an urban setting (94%)

**Mode of Infection**



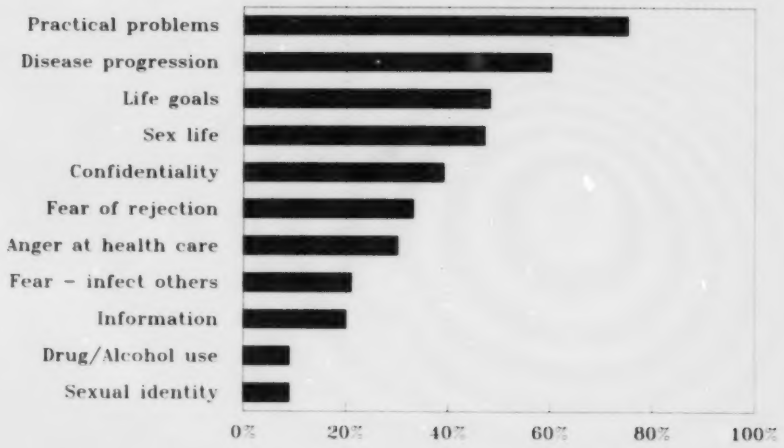
*"The professionals should listen and learn from the people living with HIV."*

*"Some well-meaning and excellent caregivers are woefully ignorant about homosexuality. They can be judgmental at times."*

*"So you have someone who's not doing very well ... He may have ... tremendous problems financially. So here he is packing up and getting on a bus which is an onerous task and expected to get to [a large centre for medical care]."*

***HIV Disease and Mental Health***

## Table 1. Problems Identified by People Living with HIV




has produced hitherto unseen levels of denial, distress, anxiety, anger, guilt, disruption and confusion.

According to the information collected through the needs assessment, the younger the individual, the greater the stress: younger people worry more about being rejected, have less developed coping mechanisms, have more concerns about their future, are more likely to have problems with substance abuse and tend to be angrier at the health care system.

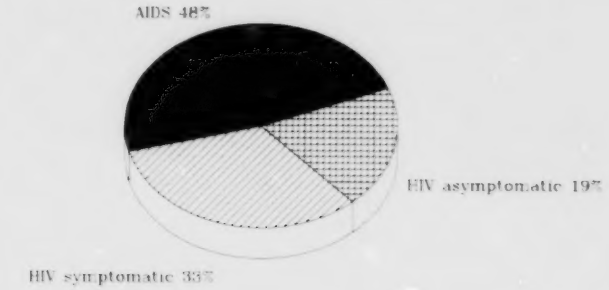
Table 1 shows the major problems people living with HIV identified through the needs assessment.

The type or frequency of problems did not vary significantly across Canada with one exception: anger at the health care system was expressed most frequently by individuals recruited through member organizations of the Canadian AIDS Society and least frequently by individuals in Toronto, perhaps reflecting the availability or accessibility of services. A large majority identified socio-economic problems — such as housing, income, legal and other practical needs — as their main concern. This reflects the fact that 23 percent of the people surveyed reported that HIV disease had had a negative effect on their work and 50 percent noted that it had changed their financial situation for the worse. Slightly over half (54 percent) of those surveyed were not working (although this ranged from 39 percent in Toronto to 75 percent in Vancouver). Only 44 percent reported employment as their main source of income while 54 percent relied on social assistance and other sources, such as disability insurance, pension, unemployment insurance and private sources.

## The stages of infection

Coping with the progression of disease is also a major source of stress. Individuals will experience different psychosocial problems and reactions at various stages of the illness.

Health Status of People Living with HIV who Completed the Needs Assessment




## Before diagnosis

The virus can have a psychosocial impact even without infection. Individuals who are or believe they are at risk (sometimes called the "worried well") suffer from panic attacks, generalized anxiety, preoccupation and various social disruptions. The longer someone is at risk — even if the person is still seronegative — the more his or her ability to function socially will suffer. Making the decision to be tested and to learn one's HIV status is also stressful.

## Diagnosis

Reactions to a positive diagnosis range from stoicism to panic. The individual's reaction depends on:

- how well prepared he or she was (pre-test counselling)
- the number of previous HIV tests he or she has had
- the person's basic psychological state
- his or her ability to cope with stressful events
- the type of contact or support he or she has with family and friends
- previous experience with friends testing positive

## Asymptomatic HIV

Individuals who test seropositive but who have no symptoms of illness, suffer active psychosocial crises when their worst fears are confirmed. Reactions such as shock, fear, depression, anger, guilt and hypochondriasis and a variety of social,

domestic and occupational disruptions are common. Because they have no symptoms, some individuals experience denial.

People who are asymptomatic generally fear the loss of confidentiality and the discrimination that may occur if and when others learn they are infected. They worry about infecting others. They also become anxious about disclosing their diagnosis. Whom should they tell? How will friends and family members react? They also face the anxiety of telling sexual partners that they may have been exposed to HIV.

Even if someone with HIV disease has no symptoms, he or she lives with the constant fear of becoming ill. With the diagnosis, many healthy people are suddenly labelled unhealthy and, in fact, their health is compromised by the knowledge they are infected. They must find a way to live fully, without denying the reality of HIV. Many will also have to change sexual and other behaviours (e.g., alcohol or drug use) to safeguard their own health and to avoid infecting others. Change is very difficult, and their ability to sustain or develop meaningful relationships may suffer.

### Symptomatic HIV

When people living with HIV disease begin to develop symptoms, the stresses change again. Persistent uncertainty about health can be accompanied by intense psychological symptoms (see Psychological Impact of HIV). Some people with HIV disease — particularly those living in remote or rural areas — may not know what services are available or they may not be able to get the services they need. Lack of medical and psychosocial care or the need to travel long distances for care are major sources of stress and anger. While individuals in Toronto, where services for HIV are well developed, reported little anger at the health care system, individuals in other parts of the country were very critical of the services available. If the care is insensitive or if hospital staff react with fear or aversion, then the stress increases.

At this stage in the illness, some individuals become completely immersed in HIV disease and their medical care. Most individuals who develop symptoms are looking for any treatment that may control the virus and prolong their lives — even unproven and experimental drugs. In response to their demands, governments and drug companies have arranged for compassionate access to a number of drugs and drug trials. However, it is difficult to make the decision to begin a drug treatment, and the course of the treatment itself is also very stressful. If the individual must pay for expensive drugs (costs can run as high as $2,000 a month) he or she may also become anxious about finances or fear that the drugs will be taken away when the money runs out. The prohibitive cost of the drugs and the time delays in drug trials are major sources of stress and anxiety. In many parts of Canada, only individuals living in or near major research centres can get the drugs; people in or near small or rural communities often go without.

At this stage of the illness, many may also develop severe worries about housing and money which can seriously threaten their ability to fight the progress of the virus. They may worry about losing control and become concerned about their legal affairs and the need for wills, powers of attorney and other safeguards.

In spite of the stress of being symptomatic, some individuals experience a sense of well-being. Some say, "The prospect of imminent death allows me to live." They are more actively involved in fighting the disease, and they receive the more intense social support and care that family, friends and caregivers offer in time of illness. They benefit from the feeling that something is being done and that people care.

## AIDS

When people develop AIDS, new stresses occur with each new manifestation of the illness (e.g., neurological disease, opportunistic infections, cancers). The individual may react with:

- shock
- fear of death, dying, being deserted or infecting others
- feelings of powerlessness, frustration and anger
- anxiety
- a loss of body image
- a change in cognitive abilities
- a change in sexual functioning
- social, domestic and occupational losses and disruptions
- behaviour disruptive to self and others
- thoughts of suicide

The individual may also react with a sense of relief or certainty at finally knowing "where he or she is going." At this stage, the individual may experience intense personal changes and exhibit a strong commitment to others.

If, in addition to coping with the stress of illness, the individual must worry about meeting basic needs — such as housing, income and food — his or her ability to cope will be severely threatened. Legal concerns become more important, and the individual may need to be reassured that his or her wishes for the future — such as the choice to refuse all or certain forms of treatment or the choice of a substitute decision-maker — will be respected.

As the disease progresses, the individual will also have to come to terms with a loss of independence, the need for palliation, feelings of grief and the prospect of death. This process often includes requests for assisted suicide or euthanasia. HIV disease has highlighted the need for more open discussion of the clinical, legal, moral and ethical implications of assisted suicide.

## The Spiritual Impact of HIV on People Living with HIV

***"What [people living with HIV] expect of us is that we have faith in them, that we believe in that inner strength they may not even be aware of, that we show confidence in them."***

HIV raises deeply spiritual questions about the nature of pain, the meaning of suffering, the connection between action and punishment, control, community, death and life after death. As with any other potentially terminal illness, HIV and AIDS highlights the human need for hope, empowerment and meaning in life.

People infected by the virus report they feel alone and often powerless and hopeless. They feel impatient, angry and guilty about their illness, and fear rejection and discrimination. Sometimes they blame God for their feelings of hopelessness and despair and for allowing AIDS to happen; sometimes they blame themselves.

Spirituality may include:

- a personal need for a system of belief or faith which both includes and extends beyond the physical self
- a locus of power and empowerment which provides opportunities for self-realization and community
- a system of unconditional meaningfulness and purpose which provides the self with a sense of positive direction and the possibility of fulfillment

Spirituality can be a source of strength, helping people with HIV, their partners, families and friends deal with emotional stresses such as alienation, despair, fear of death, and meaninglessness, and with feelings such as a sense of belonging, presence, gratitude, joy and love.

HIV has caused spiritual turmoil and confusion in the lives of people affected, and this turmoil threatens the integrity of the self. Individuals must choose to either live with HIV disease or see it as a death sentence. They struggle to find meaning for their lives and their deaths. Part of the spiritual crisis is due to the isolation, alienation and feelings of rejection inherent in HIV; another part is due to the constant pain of loss and grief.

Living with HIV, individuals are often led to confront their existing systems of belief — and often they find them wanting. Although some religious institutions are responding to the needs created by HIV, many of those affected find their needs are not being met and are looking to non-traditional sources of spirituality for support.

### Coping with the spiritual stress of HIV

People attending the caregivers conference told us that, to maintain their spiritual health, people affected by HIV must be helped to recognize their personal limits and be willing to accept the help and support of others. Individuals report that it is important to share experiences and develop a new community that supports the development of inner strength. With others who share a common spiritual search, individuals may also overcome the isolation, alienation and loneliness that is such a devastating part of this illness. Within that community, individuals who learn the important skills of listening, support and self-reflection find they develop

inner resources and can help others. Individuals who have made a conscious effort to reconnect with their emotions say that the intellectualization of emotions is one of the critical barriers to authentic and enduring spirituality.

People who are living with HIV or affected by the disease and who are prepared to share their stories can be a wonderful source of education for members of organized religion and others.

## The Psychological Impact of HIV on People Living with HIV

People living with HIV who do not have psychosocial support or coping skills may develop many varied and severe psychological reactions.

### Paradoxical desires: wanting to die, wanting to live

*"All the patients I've seen who are seriously ill want to talk about assisted suicide. I think it's time we stopped avoiding this issue and gave people a place where they can talk openly about it."*

Individuals with HIV are often torn between the desire to survive — in spite of physical, psychological and social problems — and the desire to die quickly — before the illness robs them of health, vitality and control. During the course of the infection, a high proportion of individuals who are HIV positive consider suicide (recent research indicates that the risk of suicide among people with HIV can be 36 times that of the general population).

Living with HIV is not easy. The shock of diagnosis and the knowledge that there is no cure can quickly lead individuals to thoughts of suicide or self-destructive behaviour. Underlying the desire to die is fear: fear of not having the strength to suffer, fear of abandonment, fear of dying alone, fear of losing control. These fears of the unknown are enough to unleash the desire to control one's own death.

This paradoxical desire is typical of people with HIV who have suffered multiple and successive personal losses to the illness and who, in many cases, have lost friends and partners to AIDS. They are, in effect, in a perpetual state of mourning.

Not only are they dealing with physical decline and the collapse of their immune systems, they often must cope with rejection and the loss of their psychological defences. Each day, they face the threat of losing touch with themselves, with others and with life.

### Alcohol and substance use

Approximately 35 percent of people with HIV disease have a previous history of alcohol use and more than 50 percent of these individuals continue to use alcohol after diagnosis. Because of the physical and psychological effects of their drinking and their emotional instability, these individuals often have more difficulty coping with HIV. They also tend to be undernourished which compromises their immune system and makes them vulnerable to various infections. Because they are often perceived negatively by others, they tend to have less social support and may continue their self-destructive behaviour as a means of coping with their illness.

Many people who use substances are dependent on both alcohol and drugs. With this dual disorder, they are at high risk for suicide through an overdose. They also tend to use denial as a defense mechanism, denying that they have either a substance problem or any physical symptoms of HIV. Denial keeps them from getting the early diagnosis and treatment they need to support themselves and to prevent further spread of the virus.

### Pre-existing psychological morbidity

In some individuals, a positive HIV diagnosis may accentuate pre-existing psychological conditions. For example, a person with a history of dependency may become overly dependent on his or her partner or relatives. People with poor coping skills may experience more somatic symptoms, such as headaches. Individuals with HIV may also have other pre-existing psychiatric conditions, including: unresolved, delayed or pathological grief reactions, post-traumatic stress disorders which may continue to cause psychological stress. It may be more difficult for a clinician to help someone with an underlying psychological or psychiatric condition than someone who has adequate social support and no previous psychological morbidity.

*"We'd like to see something done in the area of early neuropsychiatric testing for HIV patients. We are now putting together a battery of tests that show some sound evidence of dementia or cognitive problems. The first patient we were going to test became very anxious in the first ten minutes and just left the room."*

*"Professional caregivers and primary caregivers don't seem to know how to distinguish dementia from absentmindedness, fatigue, forgetfulness, aging and sheer orneriness."*

## The Psychiatric Impact of HIV

Up to 70 percent of people with HIV will develop an organic mental disorder (delirium or dementia), 25 percent will have a major affective disorder (depression) and 17 percent will have a panic disorder. Overall, 70 percent of people with HIV disease will seek formal mental health services during the course of their illness. The following major psychiatric conditions may occur in people with HIV disease.

### Adjustment reaction

Adjusting to the diagnosis — realizing that one has a fatal illness, suddenly having to cope with emotions such as shame, guilt, remorse, grief and anxiety — can be devastating. Adjustment reaction is, in fact, the most common psychiatric disorder suffered by people with HIV, and many suffer from it without ever being formally diagnosed.

### Clinical depression

Many people with HIV experience anxiety and depression. However, with community and family support, most are able to cope and maintain their balance. A small number of individuals may develop severe clinical depression with symptoms including persistent insomnia, loss of appetite and loss of libido, suicidal or self-destructive behaviours — which the individuals cannot deal with without professional help.

### HIV encephalopathy (AIDS dementia)

For 10 % of people with HIV, AIDS dementia will be the first clinical sign of disease. For some, dementia may be the first and only clinical manifestation of the infection. However, the prevalence of AIDS dementia tends to increase progressively: 40 % to 50 % of people with AIDS will develop dementia during the course of their illness; and 95 % will have changes in brain histopathology on autopsy. However, it is only in the last few years that this neurological condition has been recognized.

HIV attacks the nervous system, including brain cells, causing a pathological state similar to the subcortical dementias of Parkinson's disease or Huntington's chorea. Although dementia, by definition, affects cognitive, motor and behavioural functions, the early stages of AIDS dementia may cause only subtle changes in personality or mood swings. During the early stage, it is difficult to diagnose AIDS dementia either clinically, with neurological tests or with radiological investigations. Many cases of AIDS dementia have gone undiagnosed. The changes in personality or mood swings are often wrongly attributed to the psychosocial or psychological impact of the illness. AIDS dementia is particularly difficult to diagnose in someone who is an injection drug user because it is difficult to distinguish the effects of the virus from those of the drug use.

As the dementia progresses, individuals will suffer:

- cognitive deficits including poor concentration, impaired memory, lack of insight, poor judgement, disinhibition, confusion and disorientation.
- emotional instability including roller coaster mood swings which are often difficult to differentiate from "functional" psychiatric illnesses such as mood disorders, panic attacks or anxiety states.
- neurological deterioration including lack of co-ordination, the inability to initiate or complete specific tasks, poor motor function (e.g., unable to walk without assistance), and loss of bladder and bowel control. Most people with HIV neuropathy also experience severe, persistent headaches and pain in their extremities — pain which may be difficult to alleviate with analgesics, even narcotics.

Symptoms of severe AIDS dementia include loss of control and the inability to perform daily activities or to recall recent events. Individuals already robbed of their future by the virus are bereft of their past and sometimes even of present relationships with partners, family members and friends.

Because people with HIV are living longer and are, therefore, more likely to develop and be diagnosed with AIDS dementia, the pressure on the formal mental health care system, partners and families will continue to grow.

## The Impact of HIV on the Mental Health of Partners, Families and Friends

When someone is diagnosed with HIV disease, the psychosocial stress on the person's partner, family and friends is almost as great as on the person (the needs assessment reported a mean distress level for partners, families and friends that was two-thirds that of people infected with HIV). Yet there are fewer services to support family members.

### The impact on sexual partners

*"I can deal with my own poor health but losing my husband and watching him die is and will be the worst thing I'll ever experience in my life."*

*"[We] have been running a support group for ... noninfected caregivers of HIV infected people. The group is divided between heterosexual and gay couples, half women and half men. People have just lapped up the chance to have this kind of support."*

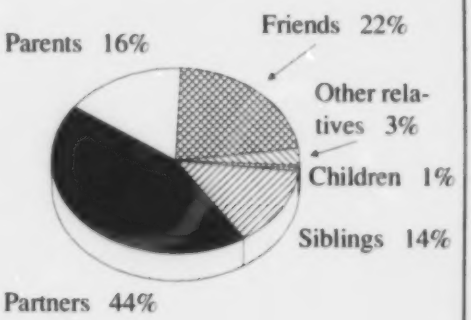
Sexual partners must cope with their concern for a spouse or lover who may become ill or develop AIDS dementia — as well as their own fear of infection and the fear of losing a life partner. Partners, lovers and spouses face intense feelings of helplessness, grief and shock as well as conflicts between their fear of infection and their desire for love and intimacy. Partners who are not infected may feel guilty because they are well and the other person is suffering. They may also suffer loss of sexual drive and overidentification with the infected partner.

Many report fear of the stigmatization of HIV and concerns about having someone be dependent on them. If the individual with HIV becomes ill and cannot work, partners are often faced with financial burdens, the responsibility for managing everything and difficulty meeting his or her own needs.

If the partner also has HIV disease — a case of two ill people caring for each other — then the situation is extremely stressful. If one partner is asymptomatic while the other is ill, they may experience

**About the Partners, Families and Friends Who Completed the Needs Assessment ...**

Of the 222 partners, families and friends who participated in the needs assessment survey, over half (56%) were male.

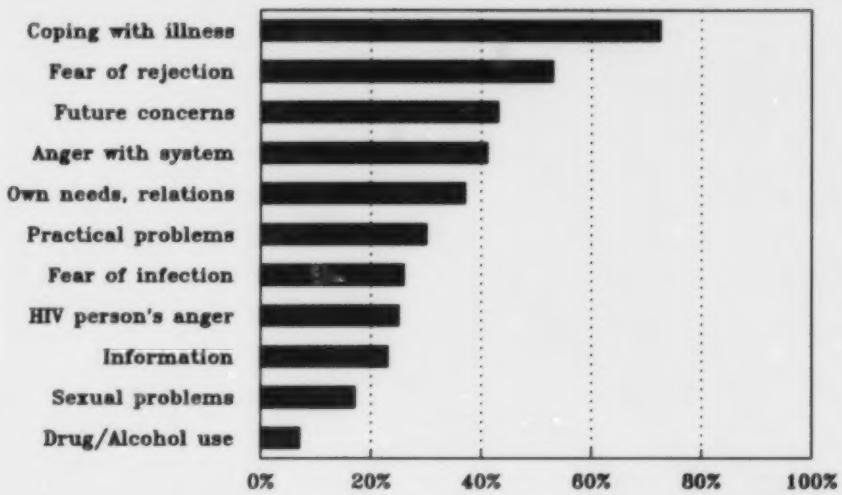



Although 80% of the partners, families and friends surveyed had daily contact with the person living with HIV and were obviously important sources of social support, only 36% claimed that the person was either completely or partially dependent on them. It appears that many people living with HIV are still financially independent — although, as indicated earlier, they are worried about their ability to manage financially.

*"It is the wellbeing of the informal caregivers that is most at risk, because they have the greatest emotional stake in the fate of the person for whom they care."*



**Table 2. Problems Identified by Partners, Families and Friends**




blame and guilt. The one who is well must deal with the emotional impact of watching the progression of HIV disease in another. The partner cannot help but identify with the other's suffering and wonder: "Will this be me in a year's time?" The couple must also deal with wills, power of attorney and the far greater risk of burnout.

Members of the working group were surprised to discover through the needs assessment that a large proportion of partners had chosen not to be tested and did not know their HIV status. However, there was no indication whether these partners simply did not want to know their status, were not accessing counselling and testing services, or did not feel able to cope with their own status while trying to care for a partner.

### The impact on parents and families

*"I watched my family assume a conspiracy of silence as everyone knew what was wrong, but all pretended they didn't as the young woman didn't want her diagnosis made public."*

Families also suffer when a son or daughter is diagnosed with HIV disease. Most people who become ill are in their 30s; their parents are at or near retirement age. At a time when they should be able to enjoy life and take pleasure in their children's accomplishments, they are faced with a sick and possibly dying adult child who may require a great deal of emotional support. At a time when they may be living on a pension, they may suddenly have to assume the financial burden of caring for someone with HIV. They may have to travel long distances to care for their son or daughter in another city, far from their own social supports. When they return home, they are often deprived of the usual funeral, mourning and grief support and must deal with the long term stress of hidden or suppressed grief.

*"What are the family's needs? Let's go beyond the infected to look at the affected ... I wanted to go in and meet with a social worker with my husband, and they did not want me in there."*

*"This is a disease that a lot of people are ashamed of. They don't want anyone to know. They only use their first names and they want it kept really confidential. They've got no one to talk to ... the solution would be to link them up with other parents ... because it's OK to talk if you've gone through it ... and if we're going to be ashamed, we can be ashamed together."*

*"[Dementia] is really hard on the families because they don't know what's happening. A son who just graduated with an MBA ... would sit at the kitchen table trying to balance his cheque book and he couldn't do it."*

If the family member comes home for care, the families may not know where to turn in their own community for the services or resources that he or she will need. Most difficult of all, they must do all this in a society that has stigmatized HIV and discriminates against those who are infected. Ashamed that their child has HIV, they may keep the diagnosis secret and therefore deny themselves the support that extended family, friends and neighbours would offer.

The pressure is greater if the adult child is gay and is not "out" to parents and family. Family members must then also cope with the disclosure of his sexuality. To care for their son, parents may have to connect with the gay community where they may not feel comfortable. Some parents — often mothers — suffer great stress struggling to keep families together through this experience. In the later stages of the illness, they may also find themselves locked in a battle of wills with their son's lover.

If the person develops AIDS and dies, parents suffer the stress and guilt of outliving their child. Traditional bereavement support services have little experience with middle-aged parents mourning adult children and may not be able to provide appropriate support.

## The stress of providing care

Many family members, partners and friends are also caregivers for individuals with HIV. In this role, they face added stress including disruption in their own lives, feelings of helplessness, the difficulty of coping with any physical deterioration in the individual (e.g., dementia, incontinence, wasting) and a sense of isolation.

One of the main sources of stress for partners, families and friends is lack of support and services for the individual with HIV. Although they are often willing to provide care for loved ones at home, partners and families become frustrated and angry if they cannot arrange for home support services or other care the individual may need. Easy access to appropriate care and services relieves some of the stress for the person infected and for partners and family members.

AIDS dementia can trigger intense emotional responses in partners and families. They often do not understand the illness and may be threatened by the person's mood changes or angered or embarassed by his or her inappropriate behaviour. At a certain stage in the illness, they will be unable to communicate with the person which may cause feelings of grief, loss and helplessness. The around the clock care someone with AIDS dementia requires adds to the stress and burden of caregiving. Partners and families often cope better when they have clearly written information on AIDS dementia and know what to expect.

Many partners and family members caring for someone living with HIV at home will incur major expenses. Some may leave their jobs to be able to provide care. While this type of care is more cost-effective and better for the mental health of the individual with HIV than hospitalization, there is no way for these caregivers to be reimbursed or compensated for what they spend or lose in order to provide care.

# III The Impact of HIV on Mental Health Services

Many people turn for some of their HIV-related mental health needs to formally organized care: physicians, nurses, hospitals, clinics, psychologists, home care, social workers and pastoral care workers. However, for the most part, formal mental health services, such as clinics, psychologists and psychiatrists have been relatively uninvolved with individuals affected by HIV disease. Although they were invited to be part of this process, very few formal mental health services prepared briefs or made presentations to the working group. It seems that, in spite of its expertise in dealing with issues related to coping with a life-threatening illness, the formal mental health sector has not yet become active or defined its role with regard to the mental health needs of people affected by HIV.

Instead, people living with HIV, their partners, families, friends and caregivers turn most often to the growing number of informal HIV-specific services and programs. These informal services include: buddies, partners, families, volunteers and community-based organizations.

Although not part of formal or traditional mental health services, these HIV-specific services are often extremely well organized, innovative and professional. According to those who presented at the hearings, these services were started to meet the urgent mental health needs of people affected by HIV. They have evolved along with our understanding of HIV disease. In general, they show a great willingness to innovate and to develop alternatives to the traditional health care system.

## Co-ordination and networking

***"What I'm disappointed with is the lack of co-ordination in the mental health field. In the city of Vancouver, we're quite well organized in terms of providing mental health care but there's been no leadership from the funding agents or from the policy producing bodies in terms of dealing with [HIV]."***

In many communities, there are an impressive number and range of services — both formal and informal — available for people affected by HIV. The problem is often not lack of services, but a serious lack of co-ordination and communication among all those involved in providing HIV-related health and mental health services. During the hearings, presenters were often unaware of other programs and services available in their area and had made little effort to link. It was also obvious from the hearings that, in general, health professionals and those working in community-based AIDS organizations are surprisingly unaware of the resources available to them and to those with HIV.

In some cases, the lack of co-ordination and networking is often complicated by what could be called territoriality. Some professionals working in traditional settings see themselves as the only experts in counselling; some working in community-based organizations see themselves as the only experts in HIV. HIV and AIDS also highlights a long-term problem in health care: defining roles, developing effective links and working relationships, and sharing information between institutional and community-based services. Resentment and tension between the two support systems may be preventing better co-operation and use of available skills and resources.

The stigma associated with HIV has also created a division between two groups in Canada most affected by the illness: individuals with hemophilia and gay men. In many communities, people with hemophilia will not go to community-based HIV or AIDS organizations for fear of being labeled as gay. The two groups often do not share their experiences or resources.

At the Caring for Caregivers Conference, special effort was made to build bridges between the communities. Individuals with hemophilia and gay men came together to discuss their common mental health concerns and learn from one another. One speaker challenged members of the two groups to "find a representative of the Canadian Hemophilia Society or the local community AIDS group and spend fifteen minutes together sometime during the weekend. If each of us does this one small thing we can have one caring network — not two or more, each resentful and envious of the others. After all, once one has acquired HIV disease, how it happened is less important than how one incorporates that fact into the rest of one's life."

Some communities have worked actively to overcome this division. For example, the AIDS Committee of Toronto has always had a member of the Ontario Chapter of the Hemophilia Society on its board. People with hemophilia and the gay community in Winnipeg worked together to organize a candlelight walk. This type of co-operation, which helps reduce the stigma associated with HIV and makes the best possible use of resources, benefits everyone and should continue.

The following describes the history and development of services to meet the mental health needs of people affected by HIV.

## Psychosocial Support for People Affected by HIV Disease

### The role of community-based AIDS organizations

*"The biggest problem we had was not in getting volunteers, but that people wanted to do more."*

*"There has to be collaboration between the agency workers and the community-based workers ... through peer support groups, through referrals. Community-based agencies offer services that, sometimes, agencies are not able to provide so there has to be a close working relationship."*

*"When the three [community support] organizations [in our province] combined all our client loads, we found that we are serving really only a third and certainly not the majority of people infected or affected in other ways by HIV ... We are not sure how these [other] people are coping or how well they are coping."*

*"A number of the patients referred to me are people who, for one reason or another, have tried the [local AIDS organization] and found that it just isn't their cup of tea. What would be really good would be to have a psychologist at the organization who could see people privately and anonymously and not necessarily get involved with the organization or in a group setting."*

Among the first to become involved in psychosocial support were members of the gay and lesbian community who mobilized as early as 1981 and 1982 to fight a new and terrifying disease that was striking down young, apparently healthy gay men. They joined with other concerned individuals to form community-based AIDS groups, which were originally all-volunteer organizations and even today draw a great deal of strength from volunteers, began with a focus on buddy support for individuals who were ill, active education to prevent the spread of the virus within the community, fund-raising to support care and research, and advocacy to counter society's lack of response to what was seen as a gay disease.

When testing first became available in 1985, most physicians knew little about the disease and could not answer patients' questions. The community-based organizations stepped in to provide the pre- and post-test counselling individuals required and ensure they understood the implications of the test and their options.

With more people being diagnosed earlier and learning to live — rather than die — with HIV, the community-based organizations have become a strong source of counselling and psychosocial support. They have developed innovative peer support programs which have helped individuals make and sustain changes in their behaviour. They have also been active in advocating for access to drugs, treatment, home care and other services. Individuals — particularly those in the gay community — turn to the community-based groups rather than traditional counselling services because of their understanding of the issues associated with sexual orientation. Their services include: buddy support, phone-line counselling and information, administration, community outreach and education, palliative care, advocacy and more. They also provide advice to the traditional health care system on education and services required for HIV. Out of the community-based AIDS organizations have grown PLWA and PLWHIV (persons living with HIV) organizations: self-help groups that are also innovative and effective sources of support.

In addition, the aggressive outreach programs of community-based organizations and their focus on peer support have proven to be a very effective way to reach other marginalized groups such as prostitutes and injection drug users. Some offer needle exchange or "bleach bottle" programs to ensure that injection drug users are educated about the importance of clean needles. The organizations have also reached out in recent years, going into schools and other forums to ensure their prevention messages are reaching the general public. However, their association with the gay community has, in some cases, been a barrier for some who need their services. For a number of different reasons, some young people, women, hemophiliacs and bisexual men often choose not to turn to community-based AIDS organizations. They may fear the stigma of being associated with groups linked to the gay community or the services the organizations offer may not meet their needs (e.g., no babysitting available for single parents).

It should be noted that most of these organizations may be dealing with different issues and offering different services depending on their size, location and

*"One of the terrifying things about getting funding is that after you've got it, what then becomes the prime directive? To stay in business and keep all those people you hired? Or to deal with people who are ill?"*

stage of development. They are often obliged to operate on very small budgets, tend to be located in second floor or basement offices in buildings often not equipped with elevators. For some people who would use their services, physical access is a problem. In some cases, these organizations do not have the resources to meet all the needs. In addition, these AIDS organizations only exist in larger centres across Canada. People in small communities or remote areas must seek services in larger centres and there is, at present, no easy way for them to link with these organizations.

The whole community-based AIDS movement relies heavily on volunteers, friends, partners and families to be active counsellors and caregivers. It has effectively mobilized a great source of strength and skills in the community. The extent to which the volunteers are trained and supported in their work depends on the age and sophistication of the organizations. AIDS committees that have been up and running since before 1985 are now fully formed community organizations, complete with training programs and systems to provide support. Newer groups may not yet be able to provide the support that volunteers, partners and families need. Even those that are well-developed are suffering from the growing demand for services as the number of people with HIV continues to increase.

Together, some 63 community-based AIDS organizations from Newfoundland to British Columbia have formed the Canadian AIDS Society, which provides support, advice and encouragement for new groups and advocates at the federal level on behalf of the organizations and people living with HIV.

### The role of partners, families and friends

*"[My son] wanted to stay at home as long as possible ... to have control, at least, over his dying ... so we were determined to keep him at home as long as we could. What we discovered is that it was a very hard thing to do by yourself. ... We had three teams: one who did actual home care ... 24 hours a day, two people on for four hours, that's a lot of people. Some people wanted to help but they didn't want to do home care so we had one team who did meals and grocery shopping. We had hot meals brought in every day from volunteers. And the other team just did odd jobs."*

Although not always organized or recognized, a significant amount of care and psychosocial support is also provided by partners, families and friends — who may or may not draw on the resources of community-based AIDS organizations or the formal health care system.

### The role of formal health organizations

Within the formal health care system, a number of different health and social service providers offer psychosocial support. Among the first to become involved were infectious disease physicians, family physicians who practice in the gay community, nurses, hospital-based social workers and chaplains, and staff in public health units.

The quality of care and the expertise of staff in hospital settings depends to a great extent on their experience with HIV. Most institutions react with fear, uncertainty and homphobia to their first cases of HIV. However, as staff gain experience, receive more training and become more familiar with the psychosocial (as well as the treatment) needs of people with HIV and their families and friends, the quality of hospital-based psychosocial support improves. A great deal of the psychosocial support that patients require is provided by the nurses who have regular, ongoing contact with the individuals with HIV and are often the ones at hand in times of crisis.

Although many hospital-based psychologists, social workers, chaplains and nurses are now more skilled and knowledgeable about HIV, people who are in-

*"Some of the real heroes in this story have been the nurses, doctors, social workers and others who have created islands of safety and compassion in the midst of large and mostly uncaring institutions."*

*"The limited experience we've had of people who have been identified as HIV positive in our program [Mental Patients' Association], leads us to believe that we're a more accessible organization for them to receive some support than other agencies in the city. It takes courage for people to connect with [an AIDS organization] and we can actually provide some basic information for people and some basic counselling around the issue until they're prepared to take that next step and become involved with the organization. So we provide a valuable kind of stepping stone for them."*

*"The real problem is that the mental health system ... is stretched to the limits right now in terms of its ability to look after the clients that are presenting themselves."*

fected are staying healthier and are hospitalized less so they tend to seek their support outside the institutions. When they are institutionalized, it is often for shorter periods of time or at the terminal phase of the illness, when they need support with grieving and bereavement issues — something that acute care settings are often ill-prepared to offer. There is very little available in the way of respite care for partners or families caring for someone with HIV. There are also few places that provide palliative care or hospices for people with HIV. Individuals referred to chronic care hospitals usually find that staff are not trained or experienced enough with the stresses associated with HIV to provide support.

Within the community, public health staff, particularly those working in sexually transmitted diseases clinics, have played a key role in the early detection, testing, pre- and post-test counselling, follow-up, education, contact tracing and monitoring of sexually transmitted diseases. Because of their experience and clinic structures, public health agencies were able to respond quickly to HIV and are now providing this same range of services for individuals concerned about HIV. Active in health education, public health departments also have a great deal of contact with the "worried well" and much of their effort is focussed on prevention rather than psychosocial support. Some operate outreach and needle exchange programs designed specifically for the hard-to-reach individuals who use injection drugs.

Formal community-based mental health services and professionals have also provided some education, counselling, support services and referrals to AIDS organizations. They are most likely to serve existing clients: that is, individuals who had been referred to them for other psychological or mental health problems or addictions. However, most mental health services have heavy caseloads and are already working to capacity. They may not have enough staff to handle the increase in demand created by HIV. Homophobia may also be a barrier to individuals receiving appropriate care and treatment from these services. Although more mental health professionals are becoming knowledgeable about HIV, many do not yet have the expertise to provide appropriate counselling services.

People living with HIV may also turn to other more formal forms of community support.

- The majority of individuals will turn to their family physicians.
- Some turn to staff in specialized HIV out-patient clinics or institutions.
- Young people who are either infected, affected or at risk may be counselled by staff in youth agencies.
- Individuals who use injection drugs may receive psychosocial support through street outreach programs.
- Women may turn to birth control clinics and traditional women's health and counselling services. However, staff in these agencies may not be trained or ready to cope with the women's HIV-related mental health needs.
- Some may seek help from private counselling practitioners or from other non-AIDS related organizations.

*"Last year we accepted the transfer of a psychotic gentleman with HIV disease, on the condition that the other hospital invite me to do a presentation to staff. I went and spoke for three hours and that type of thing is effective and useful for people working in smaller communities who don't have experience with HIV."*

Most people who are infected prefer to remain in their homes as long as possible. However, the home care services available now cannot meet the needs of a growing number of people with HIV. In many cases, home care nurses are prohibited by their rules or standards of practice from giving treatments that patients need. Those who are receiving home support services may look to the nurses for psychosocial support.

Again, the quality of both clinical and psychosocial support varies widely in different agencies and among professionals. Although more health and social service professionals are becoming knowledgeable about HIV, relatively few are actively providing psychosocial support. In large centres, individuals will often be referred to the handful of overworked professionals who do have expertise and an understanding of the complex issues. In smaller communities, there may be no one who is skilled or willing to provide care, and individuals may go without services or have to travel to larger centres.

## Spiritual Support for People Affected by HIV Disease

### The role of organized religion

*"It's hard enough to get [support] groups started in Toronto, much less in Collingwood. What allowed that group to happen, to survive? Was it the support from an organization like the Anglican Church?"*

*"I think it is the church support because if you've got clergy with a reasonable profile in the community, that gets your foot in the door."*

*"The medical skills don't solve the problem. What we tried to do in Kali Shiva is reawaken those other parts that have healed the emotional trauma that people go through."*

Traditionally, people have looked to organized religious institutions to help meet their spiritual needs. However, many individuals affected by HIV feel that, because of the dogmatic positions many organized religions have taken, they are unable to provide spiritual support. The attitude of some members of various religious bodies has fostered alienation, blame and guilt. Where clergy and organized religion have been supportive, they have been very effective in helping individuals and reducing the sense of stigma and discrimination within the community. Clergy who are involved in organizing peer support groups or openly offer counselling send a strong message of acceptance to the community — particularly in smaller centres. Some clergy have helped to provide:

- a spiritual framework for exploring the issues raised by HIV
- professional counselling and referral to a variety of support agencies
- a message of unconditional acceptance to the person living with HIV and his or her loved ones
- a means of educating the local community by example
- advocacy for the person living with HIV
- sacraments, ritual and rites of passage, especially those associated with death and bereavement

### The role of alternate forms of spirituality

One of the major impacts of HIV has been the evolution of innovative or alternate expressions of spirituality. Instead of looking outside for answers for the spirit, people affected by HIV are looking to each other and within themselves for their spiritual strength. Out of their spiritual need, people have found ways of mediating guilt and blame as well as ways to establish community and spiritual support. Dealing with the spiritual crisis caused by HIV often involves personal expressions of spirituality, including visualization exercises, meditation, Tai Chi, dance, massage and touch, which increase awareness of dynamic inner resources. Many have become involved in healing circles and self-development exercises, such as AIDS Mastery, and have found this experience very powerful and beneficial. By conceptualizing spirituality as inner strength, individuals may be empowered and enabled to access this source of power when necessary.

### The role of pastoral care

Most pastoral care workers are trained in grief and bereavement counselling and in helping individuals come to terms with fear of death, religiously-based guilt and blame. A small number of pastoral workers provide services for people with HIV at home, within institutions such as hospitals, hospices, universities, commu-

nity agencies and prisons or in specially-formed community-based groups. They provide HIV-related crisis intervention, marital and family therapy and a variety of other counselling services. For someone with HIV who has been rejected by family and friends, pastoral care may be critically important in restoring meaning, value and purpose to the person's life. Pastoral care workers also provide informal support for caregivers struggling with the stresses of HIV. As part of HIV care teams, they have helped medical and psychosocial staff face the personal, social, ethical and religious issues raised by HIV.

## Psychological and Psychiatric Support for People Affected by HIV Disease

*"I think the silence of psychologists is basically fear. When one works with an illness that is as physically devastating as this one, people become very frightened. It isn't every psychologist who will work with death and dying. In fact, not many can."*

*"We don't have a place for somebody with dementia but who doesn't need hospitalization to go and live and be looked after. They don't meet the criteria for palliative care in our hospital. We need an organized place where these people can be looked after in a caring and loving environment."*

*"The priority should be provision of some kind of creative day programs [for people with HIV who have cognitive impairments] because their needs are not being met by other traditional resources."*

*"We have a standard system of long term beds and care in this country. Somehow it seems that it is reserved for elderly people. People with psychiatric diagnosis very rarely access these facilities, let alone people with HIV. There is already a shortage of these facilities for people with chronic psychiatric problems or neurological diseases such as Huntington's or dementia."*

In some parts of Canada, clinical care for HIV-related mental health problems has been provided by existing mental health facilities — hospitals and clinics — and HIV-specific clinics. Current services include crisis intervention, assessment, treatment and follow-up (for individuals, couples, families and groups), pre- and post-test counselling, grief and bereavement counselling and pharmacotherapy. In addition, there are unique facilities such as Village Clinic in Winnipeg that combine medical and psychosocial care.

However, not all these services are uniformly available across Canada. In many locations — particularly rural areas — few if any such services exist. Even in Metropolitan Toronto, individuals can wait up to eight weeks for an assessment. Some of the gaps in services are due to lack of personnel, funding and education. During the hearings, the working group was told that most psychologists and psychiatrists have been silent and uninvolved with HIV, although that is beginning to change. Barriers have included attitudes towards homosexuality and lack of knowledge and training about HIV.

For those psychologists who are used to treating people who are physically well, HIV presents a special challenge. With HIV, psychologists must often deal with the impact of physical deterioration as well as psychological wounds so they may find it helpful to work more closely with other health professionals. Probably the most significant barrier is financial: most psychologists are in private practice and their services are not included as a benefit in most provincial health insurance systems. Many individuals with HIV would not be able to afford their services and would seek counselling and support through organizations where these services are free.

The resistance or reluctance on the part of many psychiatrists to treat people with HIV is also adversely affecting the availability of mental health care. In the 1990 membership directory of the Canadian Psychiatric Association, only six of the more than 2 100 psychiatrists listed indicated a specialty interest in HIV.

There are also currently few facilities available for people with AIDS dementia when partners, families and friends are no longer able to manage at home. Staff in long term care facilities are not trained to cope with AIDS dementia. Instead, individuals end up in acute care hospitals, which are also inadequate for the kind of care they need.

Because of the complexity of the illness and the difficulty in diagnosing clinical problems related to HIV, many individuals are not referred to the services that are available. With more knowledge about clinical mental illness related to HIV and the projected increase in the number of people who will develop these illnesses, the demand for services will grow.

## Research and Program Development

*"With the community-based AIDS movement, ... [there is the] hope that ... whether it's research or services or talking about AIDS, it will always include those living with HIV and those who are on the front line of HIV. This is a challenge for research."*

The ongoing development of mental health services for those affected by HIV is being hampered by lack of applied psychosocial research.

Most of the research in the area of HIV has focussed on biomedical issues, understanding the physical manifestations and course of the disease and assessing the efficacy and risks associated with various new, experimental drugs and treatments. Little has been done to examine the possible co-factors between mind and body and the already well-established correlation between mental state and physical condition. Although some research has been done on the psychosocial aspects of HIV, more is required — particularly on evaluating models of care and interventions.

As it has reshaped other aspects of treatment and care, HIV has also had an impact on research. Instead of using only double blind, controlled trials to test new drugs, researchers have listened to objections from the community and most trials are now open or, at least, have one open arm. Most drugs still in testing are available for those in need. The same type of demands will likely be made in any psychosocial research. To be useful, mental health-related research should reflect the needs of those most affected by HIV, be practical and provide information that will be accessible and used.

## The Psychosocial Impact of HIV on Caregivers

*Many caregivers feel consumed by AIDS work. One panel speaker [at the conference for caregivers] said he could only dimly recollect life before AIDS, and that he had difficulty imagining life in the future without the disease.*

*"Caregivers continuously confront existing spiritual values and religious dogmas and face severe challenges to these values in their work."*

*"Caregivers need to abandon the tendency to intellectualize their feelings. Instead, by repossessing their authentic feelings, caregivers may develop a sense of renewed power."*

*"Many caregivers find themselves caught in a vicious cycle of increasing work demands and longer hours on the job resulting in less time and energy available for family and friends."*

*"Because you care deeply about the needs of those who have HIV, you must also learn to care deeply about your own needs and to attend to them, so as to continue to be available to care for the needs of others. One cannot drink deeply from an empty well."*

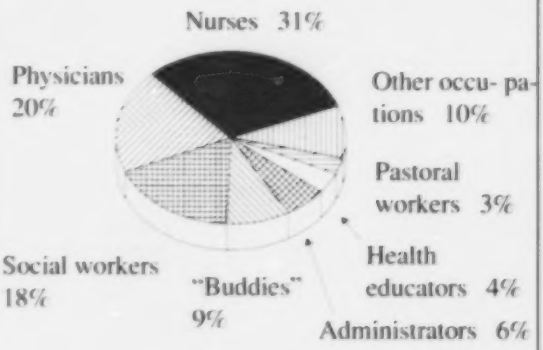
The stresses created by HIV disease have placed great demands on the full range of caregivers involved with HIV. In caring for and supporting individuals who are experiencing severe stress, they become very aware of their own limitations and those of their institutions and organizations. In spite of the innovative programs and the creative use of volunteers, professionals and resources, the majority of 459 caregivers surveyed in the needs assessment find it difficult to cope with the progression of the disease (56 percent) and feel frustrated, and many are angry with the health care system (43 percent).

Many people providing care — particularly the volunteers, partners, family members and individuals working in community-based AIDS organizations — first became involved because of the perceived inertia in the formal care system and their desire to support the gay community. Many others have become involved because of concerns about particular populations including: ethnocultural groups, aboriginal peoples, individuals with hemophilia, people who are physically or intellectually challenged, children, women, street youth, injection drug users and sex trade workers.

Caregivers tend to fall into three groups: those who are trained in clinical care but have no professional training in counselling or giving psychosocial support; those who are trained in counselling but know little about the impact of HIV; and those who have no formal training in either area but have developed skills through their experience on the front lines. Even those who are trained health professionals report that, with HIV, their caregiving role goes

### About the Caregivers Who Completed the Needs Assessment

Of the 459 caregivers surveyed, 39% were male and 62% were female.




Most (69%) were full-time workers: 70% were salaried, 12% were fee-for-service and 18% worked without remuneration. Half (52%) worked in institutions, 33% in community-based organizations and 9% in private practice. Just over half (55%) were members of an AIDS team, while almost one-fifth (19%) were gay health professionals. Two-thirds of the caregivers surveyed intended to continue their HIV-related work, while most (88%) were very or somewhat satisfied with this work.

*"Homophobia tends to be the largest stumbling block. Then there are several peculiar problems working as a physician in this specialty. First of all, many physicians are young and poorly trained for this amount of illness and despair. One is penalized financially because of the time it takes to see each patient and isolated because of the patients. The administration and frequent barricades for referrals or endless paperwork or justification for simple requests is probably more stressful than the patients themselves."*

*"I find working with AIDS patients has greatly enhanced my own personal life. Most patients are very sick when I see them, but I'm amazed at their strength of character and their willingness to try anything. I feel I receive a lot more from the patients than I ever expected."*

*"The main dangers of the stress are that people suffer from depression and that they keep distancing themselves from the patients and therefore cannot give them optimal care."*

*"It is impossible for the HIV positive caregiver to leave issues concerning HIV at the workplace, since the battle against AIDS is a personal one, located in their own bodies. The HIV positive caregiver calls this 'no exit from the trenches.'"*

beyond what they were accustomed to in other circumstances and is, in fact, being moulded by the demands of HIV. Through the national hearings, caregivers often reported that they had to "take charge" of the situation because "nobody else would." For example, a physician doing a medical examination may have to provide counselling because it is not available elsewhere in the community. A visiting nurse may provide home care for the individual with HIV as well as counselling with family members about bereavement, safe sex, contingency plans or relaxation therapy. The mother of a child with HIV may find that she must take responsibility for educating health care and school professionals about her child's illness.

This pressure to step outside traditional roles or to provide support in areas where people are neither trained nor comfortable causes stress. Aware of their own inadequacies, many caregivers complained about inadequate referral resources (26 percent) and about lack of information on HIV and the psychosocial needs of people with HIV.

Because of the intensity of the experience, caregivers often develop a special relationship with someone with HIV. Many caregivers get great satisfaction and intellectual stimulation from their work. However, the personal commitment may also cause higher levels of stress, which can lead, in turn, to burnout and stress-related dysfunction.

Because of the stigma associated with HIV, many professional caregivers are reluctant to care for people with HIV, so the burden falls on a relatively small group of professionals, paraprofessionals and volunteers. This is a particular problem with family physicians. In Toronto, where the health care system has had eight years of experience with a significant number of cases of HIV, a small group of between 20 and 30 family physicians manages over 75 percent of the individuals with HIV. While few physicians are willing or knowledgeable enough to provide care for people with HIV, those who do face the extra workload and pressure of having to prescribe and monitor experimental drugs and respond to the individual's need for psychosocial support.

Few caregivers understand or are trained to care for people with AIDS dementia so dementia cases are assigned to the few who do. The paucity of emotional, professional and peer support for caregivers may lead to feelings of inadequacy, frustration, helplessness and anger which can be directed to oneself, clients, colleagues or the institution. Dealing with people at the end-stage of their illness, caregivers may develop feelings of hopelessness, depression, constant anticipatory grief reactions and a persistent sense of bereavement.

Many caregivers are reporting high levels of stress and burnout, with symptoms such as depression, loss of interest in life, substance abuse (self-medication), resentment and devaluing of patients, a complete intolerance of or inability to retain detailed or trivial information, withdrawal, easy irritation and an inability to participate in regular hobbies and activities.

## Caregivers who are infected or at risk

Caregivers who are infected themselves or members of affected groups or at risk for infection bear the added stress of coping with anxiety and fear about their

*"As a gay man living with HIV infection for two years and having lost a lover to AIDS, I often find it easier to appreciate a client's situation. This often proves beneficial for the client, knowing that he/she is not alone."*

own health. However, according to the results of the needs assessment, this does not seem to be having a significant impact on their mental health.

Of the 459 HIV caregivers surveyed, 220 (48 per cent) reported that they had been tested for HIV and 17 (4 percent) were HIV positive. The caregivers with HIV disease were all men and were comparable to uninfected caregivers in terms of age, HIV work experience and work setting. Although HIV positive caregivers reported poorer physical health, their psychological well-being — measured in terms of life and work satisfaction and mental health distress — was comparable to that of seronegative caregivers. All caregivers, regardless of HIV status, reported the greatest difficulty dealing with the same five problems, though in differing order: grief, anger at the health care system, disease progression, helplessness and the youth of clients.

Although there is no greater psychological risk for caregivers with HIV disease, it should be noted that all HIV caregivers, regardless of their own HIV status, experience significant stress.

## Caregivers in community-based organizations

In addition to dealing with the stigma of HIV and feeling isolated from the larger community, caregivers working in community-based AIDS organizations report the following stresses:

- work overload due to staff shortages
- role ambiguity because of personal involvement with cases
- exaggerated expectations from self and others
- lack of recognition for their difficult and challenging work
- lack of training and resources
- inappropriate supervision
- perceived failure on the job

Based on the data from the needs assessment, individuals working in community settings experience more distress than those in institutions. In addition, caregivers who work more than 50 percent of their time with HIV are more distressed. Caregivers working in small towns and rural areas are also more likely to suffer from a sense of isolation and from the stigma associated with HIV.

*"I am having to leave the job because of the stress. One cannot live with tragedy indefinitely. At least, I can't."*

## Caregivers in institutions

Caregivers working in health institutions often feel isolated from their peers. Conflicts may develop within care teams over the delegation of responsibilities and over what HIV caregivers perceive as the ignorance of their colleagues about HIV. Individuals within institutions who care for people with HIV are often called upon to assume the role of experts as other professionals "dump" anything to do with HIV on them — although they may not be adequately prepared to assume this responsibility on top of their regular duties.

These caregivers complain about lack of training and resources, and often find little support for their needs within the institutions. They become frustrated over the lack of referral resources and the problems involved in getting information from another institution or from a community agency. Depending on the character of the institution, its corporate ability to deal with difficult issues, its HIV policies and protocols and its leadership, the mental health needs of caregivers may not be met. Some caregivers suggested that the structure of many institutions actually prevents them from sharing their experiences with one another, and benefiting from peer support. Others talked about discipline barriers: doctors, nurses and social workers tend to work only within their occupational boundaries and do not share or exchange information. Many are also concerned about continuity of care which depends on the flexibility of people within the institution to work across departments (e.g., Can a caregiver working in the outpatient department follow an individual who becomes an inpatient?).

The problems and stresses that caregivers working in health institutions experience are magnified in other institutions, such as prisons, facilities for the intellectually challenged, treatment centres and psychiatric hospitals. Individuals working in these settings are less likely to have the information, training or supportive policies they need to cope with HIV. They are more likely to feel overburdened, inadequate and isolated from their peers.

***"I've had a lot of negative feedback from family and friends about my possible exposure to HIV from working with these people."***

## The impact on caregivers' personal lives

Individuals providing care for people with HIV — regardless of the setting — experience extra stress if they do not have the support of their partners and families. The feeling of being consumed by HIV can strain the caregivers' personal relationships. Sometimes partners and families resent the caregiver's commitment and the time spent away from the family. Sometimes partners and family members have their own homophobia or fears of infection, which may cause them to withdraw from the caregiver. From the hearings, it was clear that this has been a particular problem for many nurses working in the field.

# IV Needs, Barriers and Coping Skills

*"I think if you provide a person with the virus with some sort of control by giving him more info on drugs and treatments and their side effects, so he can make some decisions, it would give him back a bit of control. With the AIDS virus, it seems that the one thing you lack is control."*

*"There is a lot of stress created by the fact that income assistance ... provides $447 a month for a single person, which is not enough for someone to live on."*

*"A prolonged life with the virus should not mean that our families end up further in financial debt."*

## Needs

People living with HIV who participated in the needs assessment identified the services they need most (Table 3). The strong focus on financial assistance reflects the uncertainty of HIV and the fears that most individuals have about their economic future and their standard of living.

***HIV Disease and Mental Health***

**Table 3. Services Needed by People Living with HIV**

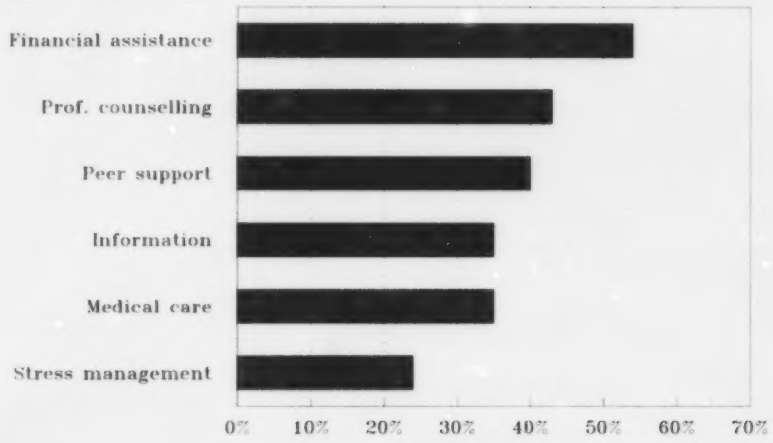
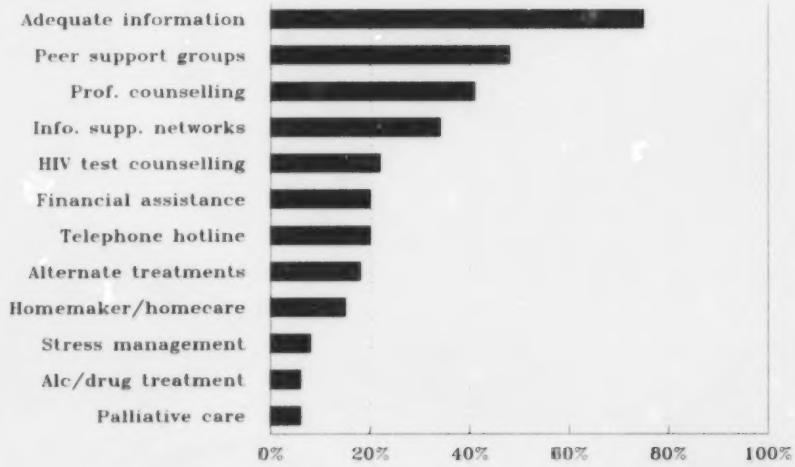



Table 4 lists the needs identified by partners, families and friends.

***HIV Disease and Mental Health***

**Table 4. Services Needed by Partners, Families and Friends**



*"Home care is essential. I spent most of my time caregiving, cleaning, cooking, driving and shopping. I would have liked to have more social time to help [my brother] through this last five years."*

In many cases, the needs that partners, family members and friends identified were not their own needs but those of the individual with HIV. Those needs varied depending on the stage of illness. For example, partners and families who had a loved one die of AIDS felt that homemaker services and hospice and palliative care were most important. Those whose family member was symptomatic felt that professional counselling was the most urgent need.

It is interesting to note that the need for hospice and palliative care was identified more strongly by partners and family members than by the individuals with HIV. This may indicate that people with HIV are focussing on living with HIV, while those around them are thinking about the services and supports that the person may need in the future.

Like partners, families and friends, caregivers suffer stress when the needs of the people with HIV are not met. Better care, services and support for those infected will do a great deal to reduce the stress on caregivers.

The needs identified by caregivers, are listed by profession in Table 6, along with the problems identified by each profession. A detailed list of the specific needs identified by the three groups surveyed is included in Table 7.



## Table 5. Service Needs by Relationship with the Person Living with HIV

Parents
- Professional counselling
- Information
- Peer support groups
- Informal support networks
- Homemaker/homecare
- Financial assistance

Partner / Lover
- Information
- Professional counselling
- Informal support networks
- Peer support groups
- Financial assistance
- HIV pre- and post-test counselling

Spouse
- Professional counselling
- Information
- Informal support networks
- Peer support groups
- Homemaker/homecare
- Alternative treatments
- Financial assistance

Sibling
- Peer support groups
- Information
- Professional counselling
- Stress management
- Informal support network

Friend
- Information
- Peer support groups
- Informal support networks
- Professional counselling
- Financial assistance

## Table 6. Problems Identified and Services Needed by Caregivers
**(in order of frequency)**

| Caregivers | Stresses | Services Needed |
|---|---|---|
| Volunteers | Anger/frustration at health care system<br>Dealing with disease progression<br>Feeling helpless<br>Inadequate referral resources | Peer support<br>Continuing HIV education<br>Expertise of formal AIDS team<br>Information services<br>Professional counselling<br>Workshops on grief/bereavement |
| Counsellors | Anger/frustration at health care system<br>Grief due to loss of friends/clients to AIDS<br>Burnout<br>Feeling helpless<br>Inadequate referral resources<br>Dealing with disease progression | Continuing HIV education<br>Expertise of formal AIDS team<br>Information services<br>Peer support<br>Professional counselling |
| Social Workers | Inadequate referral resources<br>Anger/frustration at health care system<br>Dealing with disease progression<br>Youth of clients<br>Coping with terminal illness | Peer support<br>Expertise of formal AIDS team<br>Information services<br>Continuing HIV education<br>Professional counselling |
| Nurses | Dealing with disease progression<br>Youth of clients<br>Feeling helpless<br>Inadequate referral resources<br>Coping with terminal illness<br>Anger/frustration at health care system | Continuing HIV education<br>Peer support<br>Expertise of formal AIDS teams<br>Information<br>Professional counselling |
| Pastoral Care | Grief due to loss of friends/clients to AIDS<br>Dealing with disease progression<br>Issues around confidentiality<br>Youth of clients<br>Spiritual issues<br>Inadequate referral resources | Peer support<br>Stress management<br>Expertise of formal AIDS team<br>Information services |
| Psychologists | Inadequate referral resources<br>Dealing with disease progression<br>Anger/frustration at health care system | Continuing HIV education<br>Peer support<br>Expertise of formal AIDS team |
| Physicians | Dealing with disease progression<br>Anger/frustration at health care system<br>Feeling helpless<br>Burnout<br>Inadequate referral resources | Continuing HIV education<br>Expertise of formal AIDS team<br>Peer support<br>Information services<br>Referral services |
| Psychiatrists | Dealing with disease progression<br>Anger/frustration at health care system | |

## Table 7. Specific Needs Identified Through Needs Assessment (Written In)

| | People Living with HIV | Partners/Families/Friends | Caregivers |
|---|---|---|---|
| **Financial Needs** | • subsidized or free drugs<br>• subsidized alternative treatments<br>• subsidized nutritional supplements<br>• subsidized 24-hour nursing care<br>• subsidized dental care<br>• reimbursement for health-related expenses<br>• disability/health insurance<br>• emergency financial aid<br>• low-interest bank loans<br>• financial assistance for non-governmental support organizations and self-help groups<br>• better welfare system | • financial services<br>• financial assistance<br>• life insurance for people who have HIV disease<br>• drug insurance<br>• financial support for alternative treatments | • higher income for welfare recipients<br>• public assistance for medications<br>• adequate resources<br>• free medications |
| **Practical Assistance** | • job retraining<br>• employment<br>• social and recreational activities<br>• transportation to medical appointments<br>• augmented home services<br>• adequate food banks<br>• help with household chores<br>• daycare for children of HIV+ parents | • transportation for people with HIV<br>• food delivery service<br>• workers to help with paperwork<br>• adult day care<br>• respite care during evenings<br>• homemaker services during vacations | • legal services<br>• translation services<br>• social/recreational activities<br>• day care<br>• a red-tape cutter<br>• help with paperwork<br>• political lobbyist<br>• organization within gay community |
| **Housing** | • affordable/accessible housing<br>• hospices<br>• rural retreat<br>• long term care facilities | • access to affordable housing<br>• hospice with and without religious affiliation | • long-term care facilities<br>• housing for PWA's<br>• foster homes<br>• housing directory |
| **Peer Support** | • peer support groups for HIV+ people with hemophilia, aboriginal peoples, HIV+ fathers, women, francophones, blacks, heterosexuals<br>• companionship<br>• more HIV+ buddies<br>• places and occasions for people living with HIV to meet and exhange information | • peer support groups<br>• peer support for children | • peer support groups for people with HIV, volunteers, women, children, professional caregivers, native people, heterosexuals with HIV<br>• women's centre<br>• healing circle<br>• buddy support system<br>• risk reduction groups for intervenous drug users<br>• monthly AIDS network meetings |
| **Counselling** | • financial counselling<br>• pastoral, spiritual counselling<br>• nutritional counselling | • professional counselling<br>• an understanding, compassionate person to talk to<br>• nutritional counselling | • bereavement workshop/counselling for families<br>• financial counselling |

| | People Living with HIV | Partners/Families/Friends | Caregivers |
|---|---|---|---|
| **Counselling (cont.)** | • psychological counselling<br>• medical counselling<br>• legal counselling<br>• free professional counselling through non-governmental support organizations<br>• confidential help that is not offered by gay professionals<br>• counselling on sexual practices, bereavement, dying, dementia, stress management, positive thinking and experimental treatments<br>• counselling for employers | • workshops to deal with death and dying<br>• legal counselling<br>• in-home counselling<br>• help for heterosexuals from community groups<br>• volunteer support | • nutritional counselling<br>• professional counselling for caregivers<br>• workshops on dealing with anger directed at caregivers<br>• stress management<br>• peer counselling |
| **Information/Education** | • maintaining one or two sexual relationships<br>• HIV disease — particularly for people recently diagnosed<br>• assisted suicide<br>• accessible social services<br>• travel restrictions<br>• treatments<br>• blood test results<br>• an AIDS survival manual<br>• an AIDS dictionary<br>• education for co-workers<br>• well-informed physicians<br>• an educated public. | • on AIDS and HIV<br>• education for young people on HIV issues<br>• education for the straight community<br>• a treatment registry<br>• better informed doctors | • more current HIV information<br>• in-service training<br>• treatment directory, information network on-line, information by mail, and a 1-800 line<br>• documentation on psychological counselling of PWAs/palliative care training<br>• workshops on lifestyle management, women's issues, physical therapy, time management, suicide prevention,<br>• resource book on AIDS<br>• funeral planning<br>• ethics and patients' rights<br>• public education<br>• videos on HIV for adolescents<br>• adequate information for street people<br>• information on risk reduction for clients<br>• information on opportunistic infections for pregnant caregivers<br>• AIDS education/mental health educators<br>• training in community organization (to challenge system)<br>• financial information services for families<br>• infection control expertise |

| | People Living with HIV | Partners/Families/Friends | Caregivers |
|---|---|---|---|
| **Medical Care/ Programs/ Services** | • more home care services<br>• better HIV-related training and education of medical staff<br>• adequate medical services in smaller cities<br>• access to experimental treatments and therapies<br>• access to alternate therapies such as: massage, holistic treatments, aroma therapy, garlic treatment, sex therapy and inpatient access to nutritional supplements | • home care<br>• foster care<br>• psychologist experienced with gay persons<br>• long term care facilities<br>• better medical care<br>• psychological, spiritual and emotional support<br>• alternative health and diet programs<br>• dental services<br>• city services replicated and available in rural areas<br>• anonymous testing<br>• massage therapy/sex therapy<br>• better communication between hospital staff and family | • more HIV caregivers<br>• more and better informed physicians, dentists, social workers, visiting nurses, psychiatrists<br>• formal, multidisciplinary AIDS care teams<br>• counsellors with knowledge of native people<br>• team of home care workers, baby sitters, foster care<br>• outpatient clinics<br>• more hospital care<br>• improved local medical service<br>• more palliative care, respite care and 24-hour home support services<br>• more drug and alcohol rehabilitation programs<br>• services for families<br>• pastoral services<br>• medical services/psychiatric support for crisis intervention management<br>• access to novel therapies, touch therapy, specialized equipment and T4 cell count equipment<br>• needle and syringe exchange<br>• better collaboration/liaison between hospitals and community health clinics<br>• community integration program<br>• more flexibility within service delivery system<br>• networking among rural professionals<br>• case supervision, coordination of available services, referral service |

## Barriers to using services

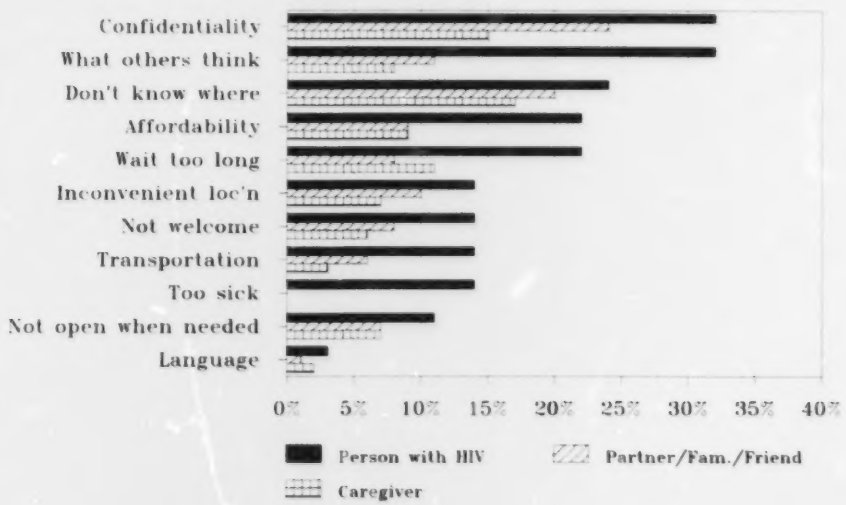
Although the people living with HIV who completed the needs assessment survey all reported unmet service needs, it is interesting to note that, with the exception of information resources, services were generally used by fewer than 50 percent of them. Those younger than 40 were more frequent users of telephone hotlines and financial assistance, while those over 40 were more likely to use peer support, homemaker services, visiting nurses and dental services.

The use of services is significantly related to the stage of illness: those who are symptomatic and who have AIDS use a greater number of available services. People who are symptomatic use more professional counselling and HIV pre- and post-test counselling services, while people with AIDS use more visiting nurse services, homemaker or homecare services, financial assistance, medical services, dental services, nutrition counselling and both inpatient and outpatient hospital services. Members of both groups use significantly more of the services offered by community-based AIDS organizations and by family physicians.

Table 8 lists the barriers that prevent people living with HIV, their partners, families and friends and caregivers from using HIV-related mental health services.

***HIV Disease and Mental Health***

### Table 8. Barriers to Using Mental Health-Related Services




For the most part, individuals in all three groups identified the same barriers. A closer look at the data indicated that individuals living with HIV who were under age 40 had more problems with lack of transportation, cost and long waiting lists. Those with less education reported that they did not feel welcome at the services, that they could not afford them and that the services were often not open at times

when they could go. People who were asymptomatic reported fear of disclosure as a barrier, symptomatic individuals talked about long waiting times and those with AIDS noted that services were often not open when they needed them or they did not feel well enough to use them. It appears that many services are not flexible enough: they tend be scheduled during working hours. Given that individuals who are employed are able to cope better with HIV, caregivers should recognize the important role that employment plays and schedule appointments not to interfere with the person's ability to work.

Individuals in rural areas were more likely to note that services were too far away or too inconvenient. When asked whether they would move in order to get the HIV services they needed, 8 percent of the people surveyed said they had already moved for that reason and 40 percent said they would. However, most believe that the services they need should be available in their communities.

The main barrier continues to be the stigma associated with HIV disease which causes people to fear the reactions of others and to be more concerned about confidentiality and discrimination than about getting the help they need.

## Coping with the stress of HIV

*"Solutions and coping mechanisms grow out of a sense of self-awareness and personal reflection. By recognizing personal weaknesses, caregivers accept that AIDS challenges their own integrity as much as that of the person who has HIV disease."*

*"The more patients and clients find strength through support groups, the more caregivers will be able to remain strong."*

The meaning of HIV and AIDS differs from one person to the next. Some describe their illness as a catastrophic test; others as a sad but beneficial psychological-spiritual experience. An individual's ability to cope with the diagnosis and illness depends to a great extent on the person's pre-morbid personality, his or her belief systems and the support he or she receives. Peer support greatly enhances the individual's ability to cope. On the other hand, negative reactions, rejection or indifference can have a catastrophic effect on the individual.

Other factors — such as education and employment — can also help individuals cope with HIV disease. According to the needs assessment, individuals living with HIV who are less educated have significantly more HIV-related problems, while individuals with higher education (at least some college) were significantly more aware of information resources, pre- and post-test counselling, alternative treatments, hospice or palliative care and other services. It is important to note that those who are working full time reported significantly fewer problems than individuals who are unemployed or unable to work.

As with the individuals living with HIV, partners and family members who are well educated and employed have fewer practical problems and are more likely to be able to find the services they need. In addition, those between the ages of 30 and 49 are more likely to be aware of alternative treatments and informal support networks. In general, men are more aware of existing services — particularly alcohol and drug treatment programs, informal support networks, telephone hotlines and respite care — than women.

Many partners, parents and family members have found peer support groups particularly helpful in coping with HIV. For example, parents of gay men with HIV disease have turned to groups such as PFLAG (Parents and Friends of Lesbians and Gays) and been able to connect with other parents living through the same experience. Not only does this provide access to information on treatment and services, but it helps reduce the stigma and isolation associated with HIV disease.

*"People who are working solely in the area of AIDS, in that very intense difficult daily work where they are seeing people die ... need a chance to get away ... there needs to be something built into the workplace."*

*"All social workers need to be trained and have access to the latest information ... they need to be supported to do this work, [and they] need skill development."*

Caregivers reported that they cope best when they have:

- peer support
- training and education
- the support of their institutions
- recognition for their difficult task
- personal skills to deal with stress
- a supportive network where they can get referral resources and discuss difficult issues
- the ability to achieve a balance between work demands and their personal lives
- the ability to ask for help when they need it

## The Needs and Barriers for Certain Populations

*"We're dealing with a population that is increasingly diverse. When I first started my job I had only gay men as patients. Now I have wives of infected individuals, children, i.v. drug users and so on. I'm becoming more aware of the breadth of this problem and the challenge of dealing with mental health with such a broad population."*

*"There is not a medical problem that does not have a moral dimension. Anyone who believes a gay man can explore the experience of being at risk for HIV disease without also considering the experience of being gay is hopelessly mistaken."*

*"Internalized homophobia is more subtle and, in some way, more dangerous than overt external anti-gay ranting."*

*"The gay male and AIDS communities have experienced multiple losses. There isn't much opportunity to process grief of individual losses let alone a collective loss that we have experienced."*

*"There is nothing more frustrating than your lover's doctor trying to pretend you don't exist instead of working together for the good of the patient. What our doctor failed to realize was that our love for one another is just as deep and meaningful as in any other type of relationship. So why are we treated differently?"*

According to the needs assessment conducted for this project, being female, younger, less educated, a student, unemployed or unable to work, dependant on welfare or unemployment insurance, living with family of birth and not living in your own place are significant risk factors for high psychosocial distress. HIV can also cause extra stress among certain groups of individuals who experience different needs and barriers to getting service.

### Gay men

Between 80 percent and 85 percent of the people in Canada infected with HIV — the individuals whose psychological status and mental health are the subject of this report — are gay men. Of those who responded to the needs assessment, 94 percent were male and 72 percent listed homosexual or bisexual activity as their mode of infection. Gay men face all the stresses already described.

In addition, disclosing their HIV status to family members may also involve disclosing their sexual orientation — or "coming out" — and the attendant anxiety. They thus must also cope with their family's reactions to the fact that they are gay as well as come to terms with living with HIV.

In addition, many gay men have had extremely negative experiences with the health care and social services systems. Because of homophobia, they have often felt rejected and have developed a level of anger with and distrust of formal social systems that may prevent them from seeking or receiving the care and services they need.

Some may internalize the homophobia that surrounds them and begin to question their sexuality and blame themselves for their infection. Many experience great anxiety over infecting others. HIV can threaten their ability to develop or maintain healthy, sexual and intimate relationships with others.

HIV has taken so many lives within the gay community, that the communities themselves are in a chronic state of crisis, grief and burnout. Having already cared for so many who are infected or who have died, partners and friends often lack the inner strength and resources to provide care, or they do so at great personal cost to themselves. One study found that gay men who have experienced a large number of losses because of HIV or AIDS develop symptoms of traumatic stress response: demoralization, sleep problems, recreational drug use and heavy use of psychological services.

Gay couples face extreme pressure and isolation because their unions are not legally sanctioned and often not socially accepted. They may not receive the support and understanding usually given to couples when one partner has a life threatening disease. If the partner has not disclosed his sexual orientation or his relationship to co-workers, he may not get support in the workplace, and the time required to care for someone with HIV may cost him his job. If the family of the person with HIV becomes involved and does not value or respect the relationship, the partner may experience rejection which may lead to resentment, anger and a loss of control.

*"Unlike other people caring for someone with a terminal illness who can expect sympathy and support, male caregivers of men with AIDS are, except within their own community, enormously isolated."*

*"Our son is a teenager with a lot on his mind. Having hemophilia makes it twice as difficult. Then comes HIV! We do not have the answers. Who do we turn to? He needs someone to talk to, to share feelings with ..."*

*"There is this real attitude of 'at the most I'll talk to you, you're certainly not going to talk to my wife and I'm not bringing my children in here.' ... there's a large measure of denial about the ... impact this is having on the entire family."*

*"My own personal experience is that there's a reluctance ... for some of these men to ask for counselling [social work] services. They have been treating themselves for years and are very capable of handling any of their medical concerns; so they tend to back off."*

*"They [the women] want to speak out. They want to break the silence, they want to stop living a lie."*

Gay men who have lost a partner to HIV disease will often not turn to traditional sources of bereavement support because of the stigma of HIV or the fear that they will not be accepted. Dealing not only with the death of a partner, but with multiple losses in the community, they may not know where to look for support except within a community that is itself coping with unresolved grief.

### Individuals with hemophilia

Of the approximately 2 500 individuals with hemophilia in Canada, 900 have HIV disease. Most are relatively young men. All are already coping with the stresses of hemophilia: a chronic, genetic illness which places great demands and strain on parents, spouses and children.

When HIV is added to what is an already difficult situation and affects two or three people within the immediate and extended family, the potential for psychosocial dysfunction in individuals — as well as within the family — is enormous.

Adults with hemophilia and their families suffer from the secrecy and silence that surrounds hemophilia and has intensified with HIV. Unwilling to jeopardize their careers by talking about their illness and trying to avoid the stigma associated with HIV, hemophiliacs keep silent and, therefore, tend to isolate themselves from society, from others with hemophilia and from possible sources of social support. Coping with HIV in isolation takes an emotional toll on the whole family.

The parents of a person with hemophilia have spent their lifetime trying to safeguard their child's health and well-being with the promise of a generally normal adulthood. With the emergence of HIV, this promise has been broken. Suddenly a child who already has a manageable life-threatening illness has another less manageable one, and the parents and families feel cheated and betrayed.

Sexual partners of people with hemophilia may be reluctant to deal with or even identify their own seropositivity because their traditional role has been to support the partner with hemophilia. The women within the families of hemophiliacs tend to be the silent caregivers for their husbands and sons. Trapped in the silence and denial that characterizes this group, they bear an incredible burden with little or no support. The Canadian Hemophilia Society recently sponsored a women's retreat, which gave many wives and mothers of hemophiliacs their first opportunity to share their experiences and strengths, develop greater self-esteem and self-confidence, and improve their mental well-being.

Individuals with hemophilia are accustomed to receiving care for their hemophilia in specialized centres across the country, and they look to these centres to treat HIV disease and provide psychosocial support. There is little doubt that HIV has severely strained the capacity of these centres, which have not usually provided mental health services. In most centres, there is only one part-time social worker who cannot meet the psychosocial demands of the hemophiliacs and their families.

*"Individuals working in the field of addictions also need to develop an understanding of HIV disease. There's been some progress, such as a Narcotics Anonymous group operating out of the PWA Coalition in Vancouver."*

## Injection drug users

Individuals who inject substances have the highest risk of contracting and transmitting HIV infection. The proportion of people whose risk factor for disease is injection drug use (either alone or combined with unsafe sexual practices among men who have sex with men) is growing steadily. Drug use can create a pressured and impulsive lifestyle which does not encourage concern for safety and may itself be a co-factor for HIV infection. Once infected, the psychosocial consequences of HIV are more devastating than in other groups. Many drug users have pre-existing personality disorders with the tendency to self-destructive behaviour.

Injection drug users tend to be more isolated than other groups and harder to reach. Not only are they dealing with multiple psychological problems, most have had extremely negative experiences with formal social structures, including social services, health care, police and the judicial system. Some have been involved in violent or criminal activities and some are unemployed. Many are very angry and do not trust the social systems to help them. They have few social supports, do not go to programs and services and frequently do not show up at a certain time for appointments. The stress of being HIV positive can intensify their drug problems.

Few mental health facilities or social services are equipped to deal with these multiple problems. Injection drug users can usually only be reached by workers willing to take the services to them. Even if they can be persuaded to enter a treatment program, there are few programs available, long waiting lists and few detox or waiting centres where they can receive treatment for their HIV disease while waiting to enter a addictions treatment program.

Caregivers are faced with the challenge of managing and treating the substance use as well as HIV disease. Treatment programs must recognize that the drive to use the substance controls the individual's life. Without the drugs, the individual may suffer distress and extreme anxiety. In spite of treatment programs, relapse and recidivism is common. However, a number of substance users have successfully overcome their addiction and many of these ex-addicts are working effectively as peer leaders in outreach programs.

## Women

As of August 6, 1991, 261 women in Canada have been reported with AIDS. Results from unlinked, anonymous seroprevalence studies indicate that the incidence of HIV infection in women is increasing.

According to the needs assessment, women seem to suffer severely from feelings of betrayal and inadequacy. They have more fear of rejection and concerns about disclosure and confidentiality. They may suffer more from a more profound sense of isolation because of the lack of support networks and because of the stigma associated with the infection. They seem to be less aware of the services available to them including: information, peer support, alcohol and drug treatment, and telephone hotline services.

Because there have been a relatively small number of women with HIV or AIDS in North America, less is known about the course of HIV disease in

women. Physicians may not recognize that women are at risk and may not encourage them to be tested. Often diagnosed later in the course of HIV disease, women also tend to survive for a shorter period of time after diagnosis than men.

During the hearings, one spokesperson talked about the problems some women face disclosing their HIV status. Disclosure reflects not only on the woman, but carries implications about her male partner's behaviours. There is, therefore, great pressure on the women not to disclose.

Women with HIV or those married to men with HIV face the added risk of infecting their unborn children. Whether they decide to delay pregnancy or conceive and risk giving birth to a child infected with HIV, the decision — for both the women and men involved — is stressful. Many women receive their diagnosis during pregnancy or childbirth so they have the added stress of worrying about the child's health and about their ability to care for the child and to have other children. If a woman is diagnosed during pregnancy, she faces the stress of deciding whether to carry the pregnancy to term and risk having a child with HIV.

Women who are infected and who are also caring for family members — a husband or child or both — who are also infected tend to neglect their own health to care for the others. Their illness threatens not only their own health but their ability to fulfill their traditional role as family caregiver.

In a study conducted in a Quebec prison, a significant number of the women inmates were found to be seropositive. All the women who were seropositive had used injection drugs. These women face the stresses associated with having HIV, as well as those of being female and injection drug users.

## Youth (age 16 to 24)

*"Having HIV is like an unravelling of the self. Just when we're getting on our feet and making decisions about what we want to do for the rest of our lives, we are faced with very adult considerations."*

At the end of 1990, 33.2 percent of adults who have AIDS were under 30 years of age. Given the long incubation period for the virus, many of these individuals were probably infected in their late teens or early 20s. Although only a small number of youth are infected with HIV, a larger number are affected because they have family members or close friends with HIV disease.

Although research has been done on the knowledge, attitudes and behaviour of youth, very little has been done to address the mental health needs of young people infected or affected by HIV.

During the national needs assessment and public hearings, the working group heard very little from or about youth with HIV. To fill that gap in information, the group held two consultation sessions in Toronto: one with professionals providing services for youth and one with youth who have HIV.

Although young people experience many of the same mental health problems as adults, their needs are more immediate. They are complicated by their age and lack of instrumental and emotional resources. Most HIV specific services are for adults, and they are not designed to meet the needs of youth who may miss appointments without excuse, require more support or call in immediate crisis. On the other hand, most traditional youth services are ill-prepared to provide counselling and information to meet the mental and emotional needs of youth with HIV.

The ability of young people to cope with HIV can be affected by their:

- maturity, self-concept, self-esteem and self-confidence

*"We have found in the years we've worked with youth if those basic needs aren't covered — housing, support, financial support and systematic support — then you can't work on HIV needs."*

*"In dealing with youth and especially street youth, they have to feel like they're involved — because throughout their lives, they've never felt involved in anything."*

- fear, homophobia (internalized and societal), stigma about diagnosis
- psychosexual development
- substance use
- feelings of loss, isolation and loneliness, disempowerment
- guilt, thoughts of suicide, denial, acting out behaviour
- burden of educating and supporting caregivers
- physical health

Some youth with HIV will also have to deal with issues of class, language, culture and race. Some are separated from their families —rejected because of their sexual orientation, drug use or their HIV status. Others have left home as part of the natural process of independence. Although they may not live with their families, many youth have been able to get a lot of emotional support from them. Some have a great desire to be reunited with their families and hope that "AIDS will bring them together again." However, this may be unrealistic.

Youth, even more than adults, are reluctant to disclose their HIV status. Some fear "people will think badly of them" and their peers will reject them. According to the focus groups and presentations at the hearings, many settings — high schools, colleges, universities, first jobs — are not known for being particularly sensitive to HIV.

Although youth may not have more crises than adults, they generally have fewer life experiences and resources to draw on in times of crisis. If they have not disclosed their HIV status to friends, they may not have informal support systems. They appear to need more support than most adults.

Many youth with HIV live on their own and either work at low paying jobs with few benefits or receive social assistance. The sudden illnesses and expenses that are part of HIV make it difficult for them to stay independent and maintain a healthy home environment. Youth with HIV need a stable income, housing and other basic practical supports to maintain their mental health.

Because they are reluctant to disclose, many youth have few safe sources of support. They do not believe that HIV or AIDS organizations can meet their needs. Because of the secrecy that surrounds HIV, the relatively small number of youth with HIV and the inability of some youth to follow through on commitments, peer support groups are difficult to form and sustain. Some young people have parents or one adult they can turn to for support.

Most of the youth with HIV are young men who are gay or who have been having sex with men as part of exploring their sexual orientation. The process of clarifying or accepting their orientation creates a number of unique mental health needs. A significant number of the youth infected are sex trade workers and substance users: two very vulnerable and hard-to-reach groups.

Many youth with HIV have trouble getting understandable and reliable information about their illness. Many are too intimidated to talk to or question their physicians. Some of the young people with HIV have never used counselling services before and they may not fit into existing youth services (e.g., they may not feel comfortable with street youth).

Because of their age or their roots in disenfranchised groups, many youth with HIV are not empowered and do not yet have the self-confidence to deal with adult systems. They are in the process of maturing, making decisions for themselves and discovering who they are. For many, HIV disease appears to be a final failure in life and getting beyond that to take control is very difficult.

*"The wife of a bisexual Greek man has two kids and she's now a widow. She talks to no one. And people are not just reluctant — reluctant would be too soft a word — to have any kind of contact with their own cultural group because of the incredible prejudice against the virus."*

*"Patients from ethnic cultural minorities ... are seeking services in hospitals because they are not able to go to their own communities."*

## Ethnocultural communities

Canada's population is made up of a growing number of different ethnic and language groups. Little research has been done on the HIV-related information and mental health needs of ethnocultural communities in Canada. However, a growing literature is beginning to emerge on the Black and Latino experience with HIV in the United States. It is difficult to extrapolate from the American experience where HIV infection in these ethnic communities is closely related to poverty, lack of education and injection drug use as well as cultural issues. However, from the little that is known, it is clear that individuals with HIV who are members of ethnocultural communities face the stresses already described, as well as others related specifically to issues of culture.

For example, their culture, language or religion may prevent them from getting the information and support they need. Information about HIV may not be available in the right language or in a form that the individual can understand. In one study of knowledge, attitudes and misconceptions about AIDS, Black and Latino adolescents were less knowledgeable and had more misconceptions than their white peers. Cultural attitudes towards sex, illness or mental health care may also keep the individual from seeking help.

Although our society as a whole is not accepting or supportive of people with HIV, some cultural groups are particularly homophobic or may completely reject those who are infected. Rejection by one's cultural group can be psychologically devastating. At the same time, because of cultural differences and his or her own homophobia, the individual may not be comfortable turning to HIV or AIDS organizations or self-help groups. Mental health professionals, paraprofessionals and volunteers may not be sensitive to cultural differences and, therefore, they may be unable to give appropriate services and supports.

It is interesting to note from the needs assessment that people with HIV who are of Asian ethnic origin were more concerned about confidentiality and rejection than were those who were Black. Blacks reported the greatest anger at the health care system and people of Latin American ethnic origin were most concerned about sexual problems. All three groups were concerned about disease progression and the future and, to cope with these stresses, they felt they needed more peer support, professional counselling and medical care.

*"We have a suicide rate three times the national average. We have a lot of sadness and a lot of hurt ... that's gone on for generations. When we started this [brief] ... [there were] 24 cases of AIDS in the aboriginal community and with that I knew the psychosocial impact would be devastating."*

## Aboriginal peoples

Because of cultural, social, political, geographic and language differences between aboriginal peoples and mainstream Canadian society, aboriginal peoples living with HIV, their families and caregivers have distinct mental health needs. Many aboriginal peoples living with HIV will not seek out services — either because of discrimination in the formal health system, their own mistrust of the sys-

*"[We need] something in place to help some of our people ... and not just for the individuals but for the family and the community."*

*"Ninety-nine percent of our mental health in your world as in our world is done by our friends and neighbours ... informal expertise should be nurtured to its fullest potential. If we can empower the people, we are much further ahead but it is important to select the right people ... I know of one case in B.C. of a young woman who has become infected and who has quite bravely gone out ... to try to educate the [aboriginal] communities."*

*"A deaf man showed up on the doorstep of the AIDS Committee. He'd seen many doctors, had many tests and reports, and yet he didn't know he'd been diagnosed with AIDS. His doctors had never used interpreters ... all the papers and files meant nothing. It was quite shocking because when you think of how much is in the media about AIDS and safe sex, there was a community of deaf individuals who weren't getting that information."*

tem or because the services are culturally inappropriate. They require services that are culturally sensitive and community-based.

Aboriginal peoples living on reserves or in aboriginal communities usually receive most of their medical and psychosocial care from CHRs (community health representatives) and psychosocial services from NAADAP (National Alcohol and Drug Addictions Program) workers. These are individuals from the communities who are specially trained to deliver certain health services and able to provide culturally appropriate care. Recognizing the growing threat to the aboriginal communities from HIV, these individuals are learning about HIV and helping to develop education, prevention, counselling and support programs.

Aboriginal peoples living outside aboriginal communities turn for services to Indian and Metis Friendship Centres, other community-based organizations — such as the Two-Spirited Peoples of the First Nation — and family physicians.

The Joint National Committee on Aboriginal AIDS Education and Prevention developed a number of specific recommendations that would help meet the HIV-related mental health needs of Aboriginal peoples and support the organizations and individuals serving them.

### Individuals with disabilities

The working group received only two presentations from organizations representing people with disabilities. Although there are few Canadians with disabilities who also have HIV disease, many of these individuals may be vulnerable to infection and to serious mental health problems. For example, individuals with intellectual disabilities have usually had inadequate education about sexuality. Lack of education and information often leads to inappropriate, risky sexual behaviour and leaves people vulnerable to abuse. A study by the G. Allan Roeher Institute (Canadian Association for Community Living) suggests that between 39 % and 68 percent of females and between 16 percent and 30 percent of males with developmental disabilities are sexually abused before the age of 18.

Some people who are hearing impaired report that they avoid doctors and other health professionals because of communication problems and because many health professionals are unaware of the cultural and linguistic differences of the hearing impaired (and other disabled) communities. As a result, they may not be receiving the counselling and treatment services they may need. Individuals who nave an interpretor to help them communicate are more likely to seek help.

People who have physical disabilities — particularly those with hearing and vision problems — lack appropriate education materials. For example, for people who are hearing impaired there are few visual materials that are produced with sign language in place of or in addition to sound. Many may not read English or French easily so they may not be able to understand most available written information on HIV. As a result, people who are hearing impaired and who are infected may not seek medical or psychosocial help until the disease process is well advanced.

In addition, someone who is disabled and who has HIV disease may find it more difficult to get the range of psychosocial supports he or she needs. For example, many people with mental disorders have been deinstitutionalized and are without alternative housing and support services. They may not be able to seek

out these services on their own. For those who are able to seek out services, those services — either in the community or in institutions — may not be physically or culturally accessible.

As there is not yet a significant incidence of HIV disease among people with disabilities, the focus with this population should be on prevention, and on providing appropriate and useful education and information.

## Individuals in prison

*"Our guys at present are being housed in segregation, and this causes a lot of stress. Their first request and desire is to be housed in open population where they have access to all the normal things other inmates have."*

*"The one fellow left at the institution who is HIV positive ... has access to some of the programs. He's a very angry and bitter young man. He feels he's being punished because he has AIDS."*

*"As long as these fellows are segregated, the message that goes out is that they've done something too dangerous to be allowed out."*

*"There's been a lot of opposition to [education] by staff. We have had several programs run but there's quite a fear."*

Researchers and prison authorities have yet to document the number of people in Canadian penal institutions who have HIV or the extent of their medical and psychosocial support needs. Most people working in the field believe the extent of the problem has been underreported.

When someone living with HIV is imprisoned, his or her continuity of care is disrupted and the network of support — if one exists — is broken. The individual must then rely on prison staff who may not be adequately trained about HIV — and who may be apprehensive and fearful — to provide care. For those who are diagnosed while in prison, they may have to rely solely on the services in the institution. Within most prisons, there is no long-term counselling or psychosocial support available for inmates or their families. Prisons are also not equipped to provide the extensive medical care that people with HIV may require.

According to anecdotal information, many prisons tend to be intolerant and homophobic environments. Many people who have HIV will not disclose their status for fear of discrimination by both inmates and prison staff. Some who have disclosed have been isolated from the rest of the prison population either for their own protection or because of a lack of understanding of HIV. This deprives them of the opportunity for occupational, recreational and socialization activities accorded other inmates. Some infected inmates will require special care or special work assignments which are not always easy to provide within a prison setting.

The isolation, stigmatization and lack of access to services and information can cause severe psychosocial distress. To address these problems, an in-depth analysis of prison society and its impact on HIV education, prevention, treatment and care is required.

# V Ending the Isolation: A Call to Action

The mental health stresses created by HIV are so complex and overwhelming that they may seem to defy action. Where do we begin to alleviate the pressure, sadness and despair caused by HIV? It is not enough just to recommend more. More services. More money. More resources. Nor is it enough to develop recommendations that individuals and organizations are either unable to implement or able to ignore.

## Analysis

Having listened carefully to so many people directly affected by HIV disease, members of the working group were able to look beyond requests for specific services to the larger problems. Listening to the wide variety of people who presented at the hearings and reading their briefs, the working group were forcefully reminded that there are serious social, environmental, organizational and structural barriers that make it difficult for people with HIV and their loved ones to seek mental health services and support. Using the data from the needs assessment, the information in the briefs and anecdotal accounts from the hearings, the working group made several key observations:

- More devastating than the virus itself in terms of mental health is the psychosocial environment — **the secrecy, stigma, religious taboos, homophobia and discrimination** — in which those with HIV, particularly gay men, their partners, families and caregivers live each day. In the view of the working group, these social attitudes contribute to much of the mental health morbidity associated with this disease. These social attitudes also threaten the health of our communities and have undoubtedly had an effect on the resources available to fight HIV disease. Without the stigma and widespread homophobia, there would be more caregivers and more support for the families and caregivers who are bearing the burden of this illness.
- The secrecy and stigma that surrounds HIV isolates people affected by HIV from the rest of society and from one another, robbing them of the community support and compassion that will help them cope. In their effort to fight the **individual isolation** that causes stress and can be so psychologically damaging, Canadians have found three main sources of strength and innovation:
  - **the courage and support provided by self-help groups.** Many people involved with HIV draw much of their strength and support from one another. While self-help programs have proven beneficial with other illnesses, they appear to be particularly effective with HIV disease. People living with HIV talk to others who are infected, partners talk with partners, mothers with mothers, sisters with sisters, caregivers with caregivers. This contact empowers those directly affected by the virus to

harness one another's energy, expertise and empathy. Self-help is a powerful source of support.

- **the commitment of people in community-based organizations** and their ability to develop creative programs and services. These individuals have been able to mobilize volunteers and empower communities to respond to this mental health crisis. They have become experts in doing a lot with few resources and in finding innovative solutions to the mental health needs of those affected by HIV disease.
- **the dedication of a small group of professional caregivers** who, often with limited support from their professional associations or their institutions, have worked to develop and provide the services needed within the infected communities.

- Individuals in small, remote communities also face the extra stress of **geographic isolation**. They often lack medical as well as psychosocial support and need some kind of lifeline to connect them to services.
- HIV disease has hit hardest among younger gay men (20 to 50 years of age), who may not have the insurance, savings or personal safety nets to cope with a long-term, debilitating and expensive illness. Unfortunately most of Canada's **social support programs are not flexible enough** to meet the practical, financial needs of people with HIV.
- In the early days of AIDS, the time between diagnosis and death was very short. However, with early diagnosis and new treatments, we no longer talk about people with AIDS (PWAs); we talk about people living with HIV. The prospect of living for 10 years or even longer, hostage to a virus that could attack at any time, creates its own stresses. In **learning to live with HIV**, Canadians will need ongoing psychosocial support and a range of counselling and support services. In addition to helping people come to terms with death, counsellors must help people come to terms with living with this illness and focus on health promotion.
- Lack of knowledge about **AIDS dementia** is preventing many people with HIV from getting the care they need. The failure to recognize or treat AIDS dementia also increases the burden and stresses on family, friends and caregivers.
- Existing health care approaches, programs and delivery systems are inappropriate for many of the individuals and populations affected by HIV disease. **Innovative approaches** are needed to reach these groups — with education, social and health services. Some are already in place; more are needed. The mental health needs of certain groups within the HIV-infected population — particularly ethnic communities and prison inmates — have been neglected.
- Canadians have been confronted with HIV disease — a new health problem — at a time of **severe financial constraint**. Forced to work with limited financial and human resources, all those involved with HIV disease must look for creative ways to mobilize existing mental health ser-

vices and expertise and make difficult decisions about how to use the resources that are available most effectively.

- To help ensure that limited resources are used effectively, more research is required in **evaluating models of care, programs, services and interventions**. Those which are effective can then be implemented in other parts of the country.
- HIV disease continues to highlight dramatically the gaps, problems and weaknesses in our health care and social service systems. Among individuals and groups involved with HIV disease, there is a surprising **lack of knowledge of the resources** available. The **lack of co-ordination** or networking among groups is further complicated by the issue of territoriality or "ownership of HIV." This threatens the ability of various organizations to work together and to make the most effective use of limited resources.

People living with HIV and their partners, families, friends and caregivers are all struggling to live and find meaning in the midst of this disease. Their concerns and their needs are closely related and intertwined. To respond and provide support, the Working Group on HIV Infection and Mental Health proposes a co-ordinated community-wide response. Only by working together as communities and as a society can we create the kind of communities, environment, organizations, structures, support, love and confidence that will allow people with HIV to find the inner strength to "transform a dead end to a path, a wall to an opening."

## A Framework for Action

The Working Group on HIV Infection and Mental Health has developed a framework for action on HIV-related mental health needs: one designed to break down the secrecy, stigma and discrimination that so strongly threaten the mental health of those involved with HIV — to end the isolation — and to fight the ignorance that keeps our communities from being supportive. The framework is based on the principle that:

> **People living with HIV disease, like any other Canadian facing a similarly debilitating, life-threatening condition, should have access to compassionate and responsive mental health services which recognize the complexities associated with HIV.**
>
> **The partners, families, friends and caregivers of people with HIV and others affected by the illness should also have access to psychosocial support and services.**

***Ending the Isolation: HIV Disease and Mental Health in the Second Decade*** consists of 10 overall goals with specific ideas for action by the federal government and by other levels of government, institutions, community-based groups and individuals. The framework is designed to build on the individual commitment and innovation that has characterized the fight against HIV in the first decade. It is designed to enhance those services which the groups who presented at the hearings told us were most effective in helping people cope: peer support and counselling. It is intended to give all those who are distressed the skills and support to cope. It is also intended to create the kind of biological, psychological, socio-cultural and socio-economic environment that will help individuals maintain the balance that is mental health.

> **In the view of the working group, there is an urgent and immediate need to pursue the following goals and strategies for HIV-related mental health services in Canada.**

## 1. Develop and foster a positive social environment, which will support people with HIV disease and those close to them and reduce the stigma that is psychologically damaging.

*"To ensure that we keep a cap on AIDS, maybe there should be [a program] to highlight leadership, motivating others, enabling others ... just bring it down to the individual level."*

Ten years of experience with HIV has shown that the more people know about the disease and about people who are infected, the more supportive they become. ***The key strategy, then, in creating a positive social environment is education.***

Governments, institutions, organizations, professions, businesses and individuals can all play a key role in shaping a more positive social environment and setting an example for society as a whole. In their efforts to educate, government institutions and organizations have a valuable resource in the people living with HIV disease and community-based AIDS organizations and should seek out their advice and learn from their experience. These individuals and organizations should also participate in planning and implementing education programs that target their communities.

To create a positive social environment, the working group suggests:

1.1 All levels of government and other institutions and organizations, such as public health authorities and HIV-related organizations, responsible for public education and prevention materials encourage a more supportive, compassionate response to HIV by:

- promoting support, acceptance and compassion in their public awareness campaigns.
- working closely with specialists in human sexuality to ensure that prevention messages — particularly those targeted at adolescents — do not have a negative impact on the ability to develop healthy sexuality and intimate relationships.
- working with youth and youth organizations to develop appropriate education and information materials for youth (e.g., rap session, t-shirts, etc.).
- actively recruiting key individuals — such as people living with HIV and their partners, families and friends, politicians, religious leaders, newspaper editors and media personalities — who are willing to speak out, help shape public opinion and create a positive environment for people living with HIV.
- organizing and conducting workshops for the media that would mobilize them to participate actively in the effort to educate and sensitize the public and encourage them to avoid sensationalizing the epidemic.
- encouraging provincial ministries of education and local school boards which have not already done so to make HIV education — which would include information and discussion

*"One of the advantages of what we do is [acknowledge] the partner in a homosexual relationship [who is often] forgotten by the institutional system. I remember one person living with HIV whose partner wasn't allowed into intensive care; his mother — who hadn't spoken to her son in 15 years — was allowed in but his partner wasn't."*

on all aspects of human sexuality — mandatory at the secondary school level and beyond.

- encouraging human rights commissions in each province and territory to recommend education approaches that would reduce homophobia in Canadian society.

1.2 The media take responsibility, through their conferences and associations, for educating themselves and developing reporting guidelines for HIV-related stories that will help reduce the stigma associated with the disease.

1.3 All workplaces — governments, institutions and businesses — which have not already done so set a positive example in their attitudes towards HIV disease by:

- using the materials prepared by the Canadian AIDS Society to develop policies that:
  - respect the right of individuals living with HIV to remain in their jobs, be free of discrimination, and have information about their health status kept confidential.
  - respect the rights of all employees to have a healthy workplace and to receive information on HIV disease.
  - recognize the needs of employees who are caring for someone living with HIV disease.
- providing training and education for existing employees about their policies on employees with HIV and other illnesses or disabilities and incorporating this education and information on these policies into orientation programs for new employees.
- updating their policies as necessary to reflect changes in knowledge and attitudes.

1.4 All health, social service and penal institutions, agencies, organizations and professions providing care for people living with HIV, which have not already done so:

- ensure supportive and compassionate care by:
  - developing HIV-related policies and procedures that will ensure that individuals with HIV disease receive appropriate, high quality, nondiscriminatory care and services.
  - developing nondiscriminatory policies that ensure sex partners receive the same respect and rights as other partners and family members.
  - educating employees about these policies.
- reduce any fear of infection on the part of staff by:
  - developing policies and procedures designed to protect caregivers from the risk of occupational exposure to HIV.

- providing continuing education for caregivers about HIV, the policies/procedures that will protect them from occupational exposure and the rights of the person with HIV disease.
- ensuring that supervisory personnel, trained to provide immediate counselling and support, are available on all shifts to respond in case of a needlestick injury.
- providing education programs for caregivers' partners and families to help them overcome their fear of infection and reduce any conflict or pressure for the caregivers.

– reduce any homophobia on the part of staff by:
  - providing special education for caregivers on sexuality, homosexuality and the psychosocial needs of gay men living with HIV disease.
  - providing education programs for caregivers' partners and families to help them deal with homophobia in order to reduce any conflict or pressure for the caregivers.
– regularly review and update HIV policies and education programs to reflect changes in knowledge and attitudes.

1.5 Health and social service institutions, organizations and professions provide training for front-line medical, prevention and counselling workers so they can assist the "worried well" and reduce the general level of HIV-related anxiety in society by:
– differentiating between those with mild anxiety and those with more severe AIDS-related anxiety or delusions.
– providing the information and support that will help people cope with mild anxiety.
– referring individuals with more severe anxiety to appropriate existing mental health services.

1.6 Whenever possible, individuals — particularly those infected or affected by the disease — be willing to talk openly about it and share their stories.

**While education is the best way to change and shape attitudes, it will not always be enough. In some cases, it will be necessary to have legal protections.** HIV disease, like other life-threatening illnesses, begs questions about the right of the individual to appoint surrogate decision-makers, make living wills and refuse, in advance, all or certain treatments. It will also be necessary to support people in using the legal system to protect their rights. The working group stresses that legislation is, in itself, a form of education because it establishes the standard for the community. To that end, the working group strongly suggests that:

1.7 All levels of government review and, where necessary, revise all legislation and by-laws pertaining to human rights to ensure they do not discriminate on the basis of sexual orientation, disability or race.

1.8 Appropriate ministries at all government levels and professional legal associations provide education to ensure that:

- the entire judicial system is aware of and respects the rights of individuals living with HIV.
- individuals living with HIV disease and the organizations providing services for them are aware of the legal support services available to help them oppose any discrimination.

1.9 All levels of government, in selecting members for appointment to the judiciary, examine candidates' decision-making record to ensure they are strong supporters and advocates of antidiscrimination legislation.

## 2. End the individual isolation that causes distress for all those affected by HIV and empower people to develop and draw on the strengths and support of self-help.

*"AIDS, like other fatal diseases, is about aloneness — aloneness now and the fear of an eternity of aloneness. We must confront this fact unblinkingly."*

*"Having three members of the family [with AIDS] ... is a blessing in one way because you have other people in the family who can understand what you're going through ... they'll understand what your fears are. The same with a wife or parent of somebody with the AIDS virus."*

*"Anything that brings people [with HIV disease] together is a caring act; anything which separates them, however well-intentioned, is not."*

*"We must recognize that some miracles happen only in the context of self-help groups."*

*"Many of the individuals ... are isolated so if we could just establish a telephone conference or network to have these individuals connect with one another and share their fears ... it would be extremely beneficial."*

Throughout the needs assessments, briefs and hearings, the working group listened to people living with HIV and their partners, families, friends and caregivers tell about their loneliness and isolation. It is time to end the isolation — both psychological and geographic — that is creating severe stress and intensifying the other mental health problems associated with HIV disease. It is time to break down the barriers that keep people living with HIV, their partners, families and caregivers from connecting with others living with the same experience.

Reducing the stigma that surrounds HIV and creating a more positive environment will help end the isolation. But more can be done. To counter the psychological isolation, the sense of being alone with this disease, the working group suggests:

2.1 Caregivers, recognizing that their clients have strengths and insights and can provide psychosocial support for one another:
- act as facilitators, helping individuals affected by HIV connect with one another.
- work with those living with HIV to organize and support self-help groups so that individuals are able to draw on one another's strength, support and understanding.

2.2 The federal government work with a community-based AIDS organization or other agency to pilot test a support group run by conference call for those who fear the loss of anonymity, but still want to connect with someone living the same experience.

2.3 Provinces which have not already done so establish information and counselling hotlines that can link people living with HIV and their partners, families, friends and caregivers with services.

To help individuals who are ***geographically isolated*** from services and support local caregivers, it will be necessary to develop innovative outreach programs. Many smaller communities will not have the caseload to justify setting up specialized HIV-related services. Instead, professionals in the community will have to be encouraged to develop enough knowledge of HIV to provide care as part of their larger practice. Therefore, the working group suggests:

2.4 The federal government continue its development of an HIV and AIDS information system, which both caregivers and individuals living with HIV disease can access.

2.5 Where clinical expertise in HIV is not available locally, provincial governments and professional associations establish innovative programs and alternatives. Examples that have been used successfully include:

- a system of regional HIV clinics.
- travelling clinics.
- buddy programs that link local caregivers with more experienced professionals in larger centres.
- exchange programs with individuals serving on HIV teams.
- apprenticeship programs.
- visiting experts who train local caregivers and then act as a resource.
- professional organizations working with local communities to recruit, train and support local caregivers willing to provide mental health services for people living with HIV and those close to them.

***"It is unreasonable to expect that everyone is going to be living in a region with a community-based AIDS group, so they'll have to make use of other organizations that will serve people affected by HIV. We facilitate that by offering a toll-free provincial line as well as counselling and referrals."***

Recognizing the ***professional isolation*** in which many caregivers work, as well as the need to act to keep experienced people from leaving the field and to recruit a larger pool of professionals to provide mental health services for people affected by HIV disease, the working group suggests that:

2.6 Community-based AIDS organizations, other community agencies providing HIV counselling and health institutions recognize the stress on caregivers providing counselling and mental health services by:

- organizing and financing peer support groups for caregivers to enable them to share their experience, vent their anger in a safe environment and reduce their isolation and loneliness.
- ensuring that caregivers have the support they require to prevent burnout.
- whenever possible, ensuring caregivers and counsellors have a mixed caseload and are not seeing only those infected or affected by HIV disease.
- developing organizational structures such as AIDS teams so that members can support one another.
- developing strong working relationships and networks with other organizations active in HIV disease.

2.7 Caregivers attempt to reduce their own isolation by:

- recognizing their limitations and saying "no" when doing so is appropriate.
- balancing their personal and professional lives.
- becoming involved in activites that foster personal growth, such as sports, recreation, meditation, Tai Chi, art, music, self-awareness programs, relaxation exercises, spirituality, retreat and time-out activities.
- pursuing programs to upgrade their skills if that will alleviate feelings of inadequacy.

***"Staff dealing with any very troubling area — such as HIV — should have some form of support group. This is difficult to do. I tried to do that at our hospital and the hospital administration found they really couldn't afford it because they would have to replace staff and there was no provision in the budget for that."***

***"We call ourselves the HIV Mental Health Interest Group and we meet once a month. Originally the group had more of a support focus and it's evolved over time ... some of the goals we've established are advocacy, support, education, research and information sharing. [We have] members from hospitals, various community services, advocacy groups, community nursing agencies ..."***

***"I think just the act of meeting together has lessened the isolation of service providers."***

3. **Ensure that all those living with HIV disease have access to financial security as well as the opportunity to participate in activities that give meaning to life.**

**People living with HIV report that financial security and other practical considerations are their most urgent need.** Yet most of our social systems are not flexible enough to meet their needs. To qualify for many assistance programs, individuals have to give up their jobs, which are often a major source of social support. To help create the socio-economic conditions that support quality of life and good mental health, the working group suggests that:

3.1 All levels of government develop alternative and more flexible forms of social assistance that allow individuals living with HIV to continue to work and still receive the financial and social support they need.

3.2 Front line caregivers and organizations providing services for people living with HIV help reduce anxiety over financial matters by:

- ensuring that, as soon as someone is diagnosed with HIV, he or she is referred to a social support network that can help the person obtain emergency funding, if required.
- encouraging individuals living with HIV to maintain their jobs or, if they cannot work, to become involved in other activities that give meaning to life.
- working closely with employers to ensure that individuals living with HIV are able to maintain meaningful employment as long as possible.

3.3 All levels of government recognize that the changing pattern of care for HIV, from the institution to the community, has moved the burden and cost to partners and families caring for someone with HIV at home and acknowledge the savings to the health care system by:

- allowing individuals to deduct the expenses of caring for someone at home from their income for tax purposes.
- supporting these individuals by funding appropriate levels of homemaker, homecare and respite services.

*"What's really important is that [counsellors] must examine their own value system before they can become effective. Have a look at their biases, their own homophobia, before they can educate others. It makes the task much more complicated."*

*"Without pre- and post-test counselling, street youth face an enormous burden. There should be no anonymous testing done in this country without pre- and post-test counselling and the counselling that is done should be standardized, progressive and involve all HIV issues."*

**4. Improve the availability and quality of counselling services. At the same time, ensure that all those providing HIV counselling services have the training and support they need to help their clients develop coping skills and to safeguard their own mental health.**

At present, counselling services for people living with HIV and their partners, families and friends vary in quality and availability. They are provided by a range of people: some volunteers, some paid professionals, some drawn to the field because of their interest or commitment to HIV, some who provide counselling as part of wider health care responsibilities. Among counsellors, knowledge of counselling skills and techniques varies widely as do knowledge and understanding of HIV.

A number of organizations have developed strong experience and skills in HIV counselling. To ensure the quality of counselling for individuals living with HIV and their partners, families and friends, the working group suggests:

4.1 The Canadian AIDS Society and appropriate professional associations review the HIV counselling training materials currently in use across Canada and select or develop materials that will:

- set Canadian standards for pre- and post-test counselling and other counselling services related to HIV disease.
- include information on counselling techniques and strategies, as well as issues such as human sexuality, homophobia, the psychosocial impact of the virus, grief and bereavement.
- emphasize in the counselling relationship the role of the person living with HIV and make clear that the type of counselling offered (e.g., group, individual, family, couples) should be based on the individual's needs.
- provide a guide that organizations offering counselling can use for initial HIV counselling training and ongoing professional development.

4.2 All organizations and individuals involved in pre- and post-testing counselling — community-based AIDS organizations, public health agencies, other community counselling agencies and family physicians — see one another as resources and recognize their ethical responsibility to ensure that individuals seeking HIV testing receive appropriate and sensitive counselling services.

*"If an individual has an opportunity to speak to somebody who's gone through the same experience and has some peer counselling training, that can be helpful. I think there's a lot of unnecessary social workers, psychiatrists and psychologists sitting down with someone newly diagnosed when maybe some of that can happen with somebody who's had the same experience."*

4.3 Each community ensure that counselling staff working at existing 24-hour crisis lines — particularly those that have contact with members of groups at risk for HIV disease — have the knowledge and capacity to provide emergency crisis counselling for those affected by HIV; and each community ensure that clients are aware this service exists.

4.4 Federal and provincial governments provide funding to support regional or provincial conferences on HIV counselling to help develop the field, improve the quality of counselling available and provide support for counsellors.

To ensure that more people become involved and active in HIV counselling, the working group suggests:

4.5 Professional health, social service and pastoral organizations and institutions increase their capacity to provide HIV counselling services by:

- developing curriculum which includes education in HIV-related counselling issues, skills and strategies.
- actively recruiting individuals who are interested in HIV and willing to provide counselling.
- providing effective continuing professional development by:
  - actively recruiting people living with HIV as well as individuals in community-based AIDS organizations, physicians, social workers and nurses who are experienced HIV counsellors to act as teachers and consultants.
  - focusing on self-teaching and peer teaching methods (e.g., videotapes and nurses teaching nurses, counsellors training counsellors.)
  - including regular articles about HIV in newsletters and other materials distributed to members and staff.

4.6 Health and social service organizations that want to develop their HIV counselling capability seek out the advice and expertise of individuals working in HIV-related organizations.

## 5. Ensure that people with HIV have access to optimal clinical management and services and to information about those services.

The purpose of this report is to look specifically at the mental health needs associated with HIV. However, the working group recognizes that access to medical services, drugs, treatment and information plays an important role in an individual's mental health and his or her ability to cope with the stresses associated with HIV. Therefore, we support the recommendations in *Caring Together, the Report of the Expert Working Group on Integrated Palliative Care for Persons with AIDS*. The working group also suggests:

5.1 Provincial governments ensure all people living with HIV have access to the full range of insured medical services and that these services include homecare, drugs, long term care, hospice and palliative care, complementary therapies and nutritional supplements.

5.2 The federal government continue its development of an information system on HIV disease and AIDS, which people living with HIV, their partners, families and caregivers can use to find the information they need to cope with the illness.

**6. Ensure that caregivers, partners, families, friends and individuals with HIV are aware of the signs, symptoms and demands of AIDS dementia and have the support and resources to provide care for the growing number of individuals who will develop AIDS dementia.**

To provide the information that people need to cope with AIDS dementia, the working group suggests:

6.1 The federal government include data on AIDS dementia as part of a proposed information system on HIV disease and AIDS.

6.2 Professional associations and colleges develop curriculum materials on the medical, neuropsychological and psychosocial aspects of HIV disease for use by psychiatrists, psychologists, physicians and others in professional training and continuing professional development.

6.3 Psychiatrists and others concerned with organic brain syndrome act as expert resources for physicians, community-based organizations and others by:

- providing in-service education on the neuropsychiatric aspects of HIV.
- helping co-ordinate the management of individuals with AIDS dementia.
- educating students in the profession about HIV disease.

6.4 The Canadian Psychiatric Association, Canadian AIDS Society, Canadian Hemophilia Society, Canadian Public Health Association and other appropriate professional groups work with people living with HIV, their partners, families and friends to develop information materials on AIDS dementia which can be:

- given to people living with HIV and their partners, families and friends.
- used by professionals to make appropriate referrals.

## 7. Encourage a comprehensive, co-operative, community-based support system, which will enhance the capacity of everyone involved to provide psychosocial services for those living with HIV and their partners, families, friends and caregivers.

*"Bereaved Families of Ontario is a wonderful organization and I think it's time organizations like that started to address the needs [created by HIV] ... [they have] to develop, promote and advertise their services so that people know that it's an OK place to come to deal with HIV-related issues, that they don't have to come to an AIDS clinic."*

*"I would like to see the Canadian Mental Health Association, the Family Services Association and other organizations recognize the unmet needs of parents and people with HIV."*

*"People tend to get referred to specialized HIV clinics ... and I think very soon we're going to be completely unable to meet demand. More generic counselling agencies and family services agencies really need to step up their role in providing these types of services."*

As HIV has become a more manageable long term illness, the focus of care has shifted from institutions to the community.

HIV services related to mental health are unusual because they have largely developed outside what is characterized as the formal mental health services system. They have attracted many volunteers and nonprofessionals, as well as trained professionals. As such they are a model for community-based care and support. However, such strong community involvement has also led to some tensions between professionals and nonprofessionals, and it challenges all HIV caregivers to find an effective way to co-operate and work together.

Individuals living with HIV will continue to seek out the care and services they need from both formal and informal settings in the community, including AIDS organizations, chapters of the Canadian Hemophilia Society, formal mental health services and other health and social service organizations.

The quality and continuity of mental health services for people with HIV will depend, to a great extent, on the ability of caregivers in all settings to co-operate, share resources and expertise, work together and support one another. Therefore, the working group suggests:

7.1 All levels of government not currently supporting community-based organizations providing HIV-related counselling and mental health services do so. Such support could take the form of:

- funding counselling and support services (as well as prevention and education programs).
- providing administrative advice, support and guidance that young community-based organizations may need to fulfill their mandate.
- encouraging networking among community-based organizations.

7.2 Community-based AIDS organizations, other community-based agencies involved with HIV and institutions within a community develop a close working relationship or network, sharing expertise and resources, identifying gaps in service and developing strategies to provide the full range of mental health services and referrals for people living with HIV. Collaboration could include:

- having one organization within the community take responsibility for:
  - maintaining an up-to-date list of available services, programs and resources.
  - ensuring all caregivers are aware of the list (e.g., newsletter or resource list).
  - encouraging caregivers to make appropriate referrals and share information about community resources with their clients.
- developing a care team to ensure continuity between hospital-based and community-based care.
- arranging exchanges between professional and nonprofessional HIV care teams.
- organizing local or regional conferences or forums to share information and develop referral sources.
- recruiting specialists in HIV counselling, social work, psychology and psychiatry to act as resources to community-based organizations and help them develop their counselling skills and their knowledge and understanding of AIDS dementia.
- developing outreach programs for groups and individuals who may not seek out services or be reached by programs in formal health settings.

## 8. Reinforce and build on the strengths of community-based HIV-related organizations.

Because of their strong roots in the community, AIDS organizations have successfully recruited volunteers and developed effective, innovative mental health programs and services. To respond to the growing demands of HIV during the second decade, community-based AIDS organizations will have to continue to be creative, flexible and capable of mobilizing large groups of volunteers and capturing the commitment of their communities. Therefore, the working group suggests:

8.1 The Canadian AIDS Society and the Canadian Hemophilia Society support the efforts of their member organizations to recruit and maintain volunteers by:

- reviewing available volunteer training materials and selecting or developing a model program its members can use.
- encouraging members to develop volunteer support, recognition and counselling programs.

8.2 The Canadian AIDS Society, the Canadian Hemophilia Society, the Canadian Public Health Association and their member organizations:

- evaluate their counselling and support programs, identifying strategies that have proven effective with specific target populations and could be expanded or adapted for use with other groups.
- explore the barriers that prevent people from using their services and either:
  - develop ways that they can move beyond serving their traditional client groups and meet the needs of others who are living with HIV, or
  - help agencies that target other populations develop the skills and expertise to provide support for individuals in those groups who are affected by HIV.

8.3 All levels of government provide funding and support, as well as clear expectations, that will encourage HIV-related organizations to strengthen their links with the community and their ability to develop community resources.

## 9. Ensure that HIV mental health programs and services are sensitive to the special needs of particular groups or communities affected by HIV.

To ensure that programs, services and materials reflect the diverse needs of ***all*** individuals affected by HIV, the working group suggests:

9.1 All settings offering HIV-related mental health services ensure existing programs respond to the needs of various cultural groups and special populations through:

- transcultural mediation.
- consultation with individuals from these communities or groups who are knowledgable about their needs and can act as facilitators, helping to develop appropriate programs and services.
- consultation with the Canadian AIDS Society, many of whose member organizations have experience adapting programs to meet the special needs of different groups.

9.2 Whenever possible, federal, provincial, regional and community HIV-related groups involve individuals from these target groups in:

- planning services for their groups.
- developing policies that may affect them.
- formulating and implementing any research related to their group's needs.

9.3 Where the prevalence of HIV disease in any one group warrants it, federal and provincial governments provide funding to enable these groups to develop mental health programs and services within their communities; where it does not, funding be given to enable community-based organizations to work with members of the groups to develop appropriate programs and services.

**Gay men are the community in Canada most affected by HIV disease. In the view of the working group, all the actions and strategies already described in this framework are designed to meet the special needs of gay men, their partners, families and friends.**

In addition, to meet the special needs of members of other groups affected by HIV, the working group suggests the following actions:

*"[The Women's Retreat] was a place where they could share ... and it was a protected environment and they could speak openly and freely, knowing that the person they were speaking to could understand what was happening."*

**Individuals with hemophilia**

To break down the silence and isolation that surrounds hemophilia and meet the needs of families where several members may be infected, the working group suggests:

9.4 Funding organizations recognize the increased pressure that HIV disease has created for hemophilia clinics and increase funding so clinics can provide more counselling and psychosocial support for infected individuals and their families and partners.

9.5 The Canadian Hemophilia Society strengthen its efforts to meet the special mental health needs of women affected by hemophilia and HIV by providing information and education, skill-building sessions and counselling services such as peer support groups and grief and bereavement counselling.

**Individuals who use substances**

To meet the distinct needs of people who are dependent on drugs or alcohol, the working group suggests:

9.6 Professional associations and HIV-related organizations work together to develop appropriate education and training programs for counsellors working with individuals who use substances. Education should cover:

- the need to treat both the substance use and the HIV disease.
- the impact that the substance use can have on the progression of HIV disease.
- the impact that the stress of HIV disease can have on substance use.

9.7 Within each community, community-based organizations providing HIV-related services, addiction treatment centres and local addictions groups work together to:

- share their knowledge and experience.
- co-ordinate services between the two settings.
- design and deliver unusually flexible and creative outreach programs.
- establish long-term supportive rehabilitation programs in a community setting, which will help individuals cope with the stress of HIV without using drugs or alcohol.

**Women**

To meet the special needs of women with HIV, the working group suggests:

9.8 Where prevalence of HIV warrants it, funding agencies consider establishing a hospice specifically for women who have HIV; the hospice should also be able to accommodate children. Where numbers are too few, women ought to be able to access general long-term and palliative care services.

9.9 Women's groups, professional associations and community-based AIDS organizations work closely with existing health and social services for women to empower them to provide appropriate counselling, social support and peer support groups for women with HIV.

9.10 Where women with HIV disease are caring for children who are also infected, provincial governments and the appropriate institutions ensure that both child and parent can receive care and services in the same setting.

**Youth**

To meet the special needs of young people living with HIV, the working group suggests:

9.11 Organizations and institutions within a community facilitate networking among professionals working with youth — both those who are knowledgeable about HIV and those who are not — to share ideas and experience.

9.12 Community-based organizations and agencies (such as churches, schools, youth groups, youth detention homes and group homes) work with youth living with HIV to:

- organize peer support groups.
- adapt successful peer education program models to respond to HIV. (e.g., In the race relations initiative, students write papers in English class to provide a context for the program and students are trained as peer educators. For the drug ambassador program, youth in the community identified the information they needed and then helped to develop it.)

9.13 Community-based organizations develop flexible services and outreach programs specifically designed to reach street youth who may not have used social services in the past, may be uncomfortable using them and may not know where to turn for assistance.

**Aboriginal peoples**

To meet the special needs of aboriginal peoples living with HIV and those close to them, the working group supports the recommendations of the *Joint National Aboriginal Strategy on HIV* and applauds the initiative that has already begun to educate Community Health Representatives (CHRs) and National Alcohol and Drug Addictions Program (NAADAP) workers to provide HIV-related psychosocial services in aboriginal communities. In addition, the working group suggests:

9.14 The federal government involve aboriginal peoples directly in planning their counselling and psychosocial services and recognize the importance of traditional aboriginal spiritual values in developing programs, services and materials.

9.15 Federal and provincial governments provide training, guidance and ongoing support to CHRs and NAADAP workers currently working in aboriginal communities so they can provide counselling, psychosocial support and appropriate referrals for those living with HIV.

9.16 The Canadian AIDS Society and and Canadian Association of Social Workers work with CHRs and NAADAP workers to develop an appropriate training program.

9.17 Federal and provincial governments provide funding so existing organizations — such as friendship centres and gay and lesbian aboriginal groups — can work with aboriginal peoples and community-based AIDS organizations to develop appropriate mental health services for those living outside aboriginal communities.

9.18 Agencies and organizations providing services for aboriginal peoples co-ordinate on-reserve and off-reserve services and make appropriate referrals.

**Ethnocultural communities**

To meet the special needs of members of ethnocultural communities, the working group suggests:

9.19 Community-based organizations already serving ethnocultural communities incorporate HIV mental health services in their programs and seek the necessary information and training.

9.20 The cultural communities identify individuals who can provide leadership and advocate on their behalf.

*"Hospitals, clinics, counselling centres all need training so they may become more sensitive to deaf culture. They don't understand that deaf people have their own language.... Hospitals also need to be able to access professional sign language interpreters (people who are able to use fluent American Sign Language) and telephone devices for the deaf."*

*"Right now is the time for us to develop the role of the deaf mental health professional. Someone who is part of the care team who is knowledgeable about mental health and is also knowledgeable about deaf culture."*

*"The inmate chairman feels that approximately 80 % [of the inmate population] would support the fellows [with HIV] coming into open population."*

*"In a special unit for people with HIV ... we can grant more privileges and we would develop staff who would become experienced. ... we could have a visiting specialist come in rather than ship people out in handcuffs and legirons to an HIV clinic in a hospital."*

*"The [local community-based AIDS organization] comes to our penitentiary ... they offer counselling, talking to the fellow, just setting up a friendship network, somebody that will come in and visit them in place of family and give them a liaison with the community. They're also willing to come in and do education for staff and inmates."*

**Individuals with disabilities**

To meet the special mental health needs of individuals living with HIV who also have disabilities, the working group suggests:

9.21 The professions develop a national HIV and AIDS education program on the mental health needs of people with chronic mental illness and HIV, and ensure appropriate services are available.

9.22 Caregivers, community-based AIDS organizations and members of disabled communities develop appropriate HIV-related education and counselling programs for people with disabilities.

9.23 Recognizing the special needs and communication problems of people who are deaf, the federal government work with the deaf community and hearing impaired to:

- develop an education program for professionals about the cultural and linguistic differences in the deaf and hearing impaired community.
- provide incentives and programs to encourage more counselling professionals to learn American Sign Language.
- provide interpretors.
- encourage deaf or hearing impaired people to consider counselling professions and become involved in HIV counselling.

**Individuals in prison**

To meet the special needs of people living with HIV who are in correctional institutions or detention centres , the working group suggests:

9.24 Whenever possible, correctional facilities house inmates with HIV disease with the general prison population where they have access to the full range of programs and activities in the institutions. If not possible, the facilities could create a special wing for seropositive inmates where they can have access to recreation, occupational opportunities and peer support.

9.25 Correctional facilities ensure inmates with HIV have access to ongoing psychosocial support and pastoral care.

9.26 The John Howard Society, Elizabeth Fry Society and other organizations providing support and services for individuals leaving prison:

- seek out advice on HIV counselling and related services from community-based AIDS organizations.
- provide appropriate ongoing support, counselling and referrals for individuals living with HIV who are making the transition back into the community.

**10. Ensure research is undertaken on effective HIV mental health services and ensure that research data is available and used to plan effective HIV-related mental health services for the second decade.**

With the exception of certain specific groups — such as ethnocultural communities and prison inmates — enough research has been done into mental health-related needs. The real gap is information on effective services and interventions. Therefore, the working group suggests:

10.1 Governments, institutions and organizations use data collected by the working group to design programs and services.

10.2 Universities, academic institutions and bio-ethics institutes take leadership and work with those providing HIV-related mental health services to develop applied research projects.

10.3 Any HIV-related research project include people living with HIV in the design and planning stages.

10.4 Federal and provincial governments support research in:

- homophobia, discrimination issues and AIDS phobia.
- the "worried well."
- the impact of HIV on the psychosexual development of adolescents and post-adolescents and their behaviour.
- the relationship between caregiver and patient.
- non-traditional healing methods.
- models of care and service development.
- AIDS dementia.
- women's and children's issues.
- street youth counselling and support systems.
- religious and spiritual factors.
- coping models.
- rural and urban differences.
- sexual attitudes and mental health needs of ethnocultural communities.
- regional (rather than national) profiles of HIV which would account for significant, subtle cultural and regional differences and sensitivities.

10.5 The federal government, perhaps through the proposed information system in HIV and AIDS, provide an index of available research with a clear, user-friendly summary of the findings.

*"AIDS is a high price to pay for anything. It would be scandalous if we were to pay the price (and we must pay it) for nothing. A better and more caring system for all sorts of chronic illness and a recognition that much health care is best delivered in the community are benefits we can exact from this epidemic."*

## Conclusion

In their struggle against HIV disease, Canadians have shown how much can be done with dedication, few resources, innovative approaches, self-help and volunteers. The challenge in the second decade will be to keep communities mobilized, build on those strengths, and end the isolation by breaking down the social, cultural, economic, psychological and organizational barriers that keep people affected by HIV from seeking and receiving the care, comfort and services they need.

***Ending the Isolation: HIV Disease and Mental Health in the Second Decade*** provides a framework and a call for action for the next decade. The working group strongly recommends that:

**The federal Department of National Health and Welfare recognize the urgent need to act to safeguard the mental health of those affected by HIV disease.**

**The federal Department of National Health and Welfare work with other federal agencies, with each province and territory, with professional organizations, with non-governmental organizations and with the private sector to create a concrete plan for community-wide action to end the isolation and meet the mental health needs of those affected by HIV disease.**

**The federal Department of National Health and Welfare establish an internal, inter-branch group to monitor the implementation of the strategies suggested in this report.**

The working group believes that history will measure our society by the way we respond to social crises such as HIV. This illness affects us all. We are all held hostage by the virus: some by infection; others by the fear and attitudes which keep us from reaching out.

Because those who are affected have told their stories, because they have been willing to collaborate, because many have already died, we dare to believe in the force of a mutual aid collective. We wish to salute the men and women whose courage to love, to speak out, to lose and to die have finally pushed us out of our individual indifference into the social battle to end the isolation of HIV disease.

# Appendices

# Appendix I

## Assessment of HIV-Related Mental Health Needs and Services in Canada

The needs assessment was carried out between August 1989 and August 1990 (with the field work carried out between February and June 1990), by a team headed by Dr. Donna Lamping of McGill University and including Maida Sewitch, Elisabeth Clark and William Ryan. Drs. Norbert Gilmore, Steven Grover and J. Ivan Williams and Ms. Carli Meister served on the steering committee. The study was financed by the Federal Centre for AIDS (FCA) and conducted under the general supervision of the FCA Working Group on HIV Infection and Mental Health.

### Methodology

The assessment was carried out by means of a survey, using a questionnaire developed on the basis of a review of relevant literature: on HIV and mental health and on the conduct of needs assessments. (The working group commissioned a literature review specifically for this purpose and copies of the review are available on request from the Federal Centre for AIDS. Little had been written about the Canadian experience with mental health and HIV disease. The material and information gathered through the review may have limitations because it was based on data and experience in the United States, where both the epidemiology of the disease and the organization and funding of health services are different.)

Three versions of the questionnaire were developed, in both official languages: one for use by clients (persons infected with HIV), one for use by caregivers (professionals and persons other than family members), and one for use by family members and significant others. They were pre-tested with a sample of 52 respondents from seven cities across Canada, and final versions were then prepared. Each questionnaire had three parts.

- The first collected demographic and background information (age, sex, ethnicity, education, residence, work and financial status) and information on health status (physical and psychological), life satisfaction and happiness. This section also contained questions specific to the particular target group: for example, the client questionnaire contained questions about HIV status, diagnosis, treatment, and illness; the caregiver questionnaire contained questions about time spent in HIV caregiving, expectations about work, and HIV status; the family member and significant other questionnaire asked questions about the person with HIV infection with whom they were concerned.
- The second part included questions related to mental health problems. It provided a list of problems identified in the literature and by key informants. The lists varied somewhat from version to version but there was much overlap. Respondents were asked to use a five-point Likert-type scale to assess the distress associated with each problem, to list any addi-

tional problems, and to identify the three most important problems from the list.

- The third part included questions about services related to mental health (broadly defined). The services listed in each version of the questionnaire were appropriate to its particular target group. There was some overlap between lists. For each service, respondents were asked to indicate which was available in their area, which they had used, and to indicate the three services that they needed most. The section also included questions relating to barriers to services (such as language and accessibility).

A final, open-ended question invited respondents to write in comments about needs, services and the impact of HIV on their work and lives.

Questionnaires were distributed through 124 key service providers (individuals associated with one of five general types of practice: primary health care facilities, community health clinics, social service agencies, community-based organizations and private practice) in four major urban centres: Vancouver, Toronto, Montreal and Halifax, and through 26 member organizations of the Canadian AIDS Society (CAS).

The key service providers were asked to enlist a particular number of respondents in each category, give them questionnaires (to be filled out without identifying themselves and returned in sealed envelopes), and send the completed questionnaires back to the research team.

In total, 1 262 questionnaires were returned (1 023 English and 239 French) by 581 clients, 459 caregivers and 222 family members and significant others; 142 of the total were from respondents in Halifax, 303 in Montreal, 349 in Toronto, 258 in Vancouver and 210 from CAS community-based groups. The estimated overall response rate was approximately 72 percent.

In terms of the distribution of sex, age, and mode of acquisition of infection, the client respondents were very similar to the Canadians reported as having AIDS. However, the client sample:

- did not include persons who have not made a connection with the formal and informal AIDS and HIV care systems, and
- may or may not have been biased toward frequently-seen, readily available or cooperative clients.

The caregiver and family member and significant other samples could not be compared to any overall statistical picture because none exists; however, the same kinds of selection biases may have existed. This may be particularly important with the family member and significant other sample, since accessibility may be more of an issue. Moreover, the distinction between a caregiver who is also a family member and significant other and a "family member and significant other" has not been clearly described; therefore there may be some overlap between these two categories. (The caregiver category included, in addition to professional health care workers, buddies or helpers, peer counsellors, and general volunteers.)

## Respondent characteristics

**Clients** (N = 581): The client sample was 94% male and 6% female, with a mean age of 36 years (range: 17 to 74 years). Most were white (87%), English-speaking (84%), highly educated (67% with at least some post-secondary education), and lived in their own homes (78%) in an urban setting (94%). Slightly over half (54%) were not working, although this ranged from 39% in Toronto to 75% in Vancouver. Main sources of income included: employment (44%), social assistance (23%), and other (disability insurance and pension, unemployment insurance and private sources) (31%).

The proportion of female clients dependent on social assistance (39%) was almost double that of males (23%), while the proportion of females drawing disability, pension, unemployment insurance or supported from private sources was closer to half that of males (19% versus 32%, respectively).

Approximately half (47%) of the clients had been diagnosed with AIDS, one third (32%) were HIV symptomatic and one fifth (19%) were HIV positive but asymptomatic. The length of time of diagnosed seropositivity ranged from 3 to 89 months. Two thirds (66%) were aware of their T4-cell counts, which ranged from 1 to 2 030; the mean count was 285 (83% had counts under 500). Two-thirds (66%) were receiving AZT or ddI treatment. Their illness was reported by 23% of the clients to have had a negative effect on their work and by 50% to have changed their financial situation for the worse.

The Toronto and Montreal samples had a higher percentage of females (9%) than those from either Halifax (4%) or Vancouver (2%). Females in the CAS sample mirrored the overall (6%) proportion. Clients were mostly Canadian-born (85%); ranging from 81% in Toronto to 94% in Halifax. Although 37% reported they lived alone, this proportion ranged from 12% in Halifax to 39% in Toronto. Two-thirds of the Montreal sample (67%) and 2% of the remaining client sample were French-speaking; two percent of the total sample were native people.

**Caregivers** (N = 459): Although the average age of caregivers in the sample was only about 2 years greater than that of clients, there was a large difference in the proportion of females: only 39% were male and 61% were female (in the Vancouver sample, 70% were female). English was the official language of almost all caregivers except in Montreal where French was the official language of 62%. A large majority (74 to 90%, except in Vancouver where it was 66%) had completed a college or university degree and a further 17% (27% in Vancouver) had some post-secondary education. Thirty-one percent (47% in Vancouver) were nurses; 20% (15% in Vancouver) were physicians (including psychiatrists); 18% were counsellors or social workers; 9% were "buddies". The remaining 22% were: administrators (6%), health educators (4%), pastoral workers (3%) and other occupations (10%); 1% were volunteers. In the CAS sample, there were fewer physicians (4%), more "buddies" (18%) and administrators (10%) and many more health educators (14%) than in the samples from the four cities.

Most (69%) were full-time workers; most (70%) were salaried, while 12% worked on fee-for-service and 18% worked without remuneration. Half (52%) worked in institutions, one-third (33%) in community-based agencies, and 9% in private practice; a few (6%) had other work settings. Their involvement in HIV-related work varied from less than 10% of their work time (20% of them) to

greater than 50% of their work time (39% of them); 16% had worked in this area for less than 12 months, 32% for between one and two years, 37% for from two to six years, and 14% for more than six years. About one third (37%) of them worked only with HIV-infected people while the rest worked with clients as well as with families and significant others and caregivers. Just over half (55%) were members of an AIDS team. Twelve percent of the CAS sample of caregivers worked in rural settings, compared with only 4% of the aggregated sample.

Nearly one-fifth (19%) were gay health professionals. Two-thirds (67%) of the caregivers intended to continue their HIV-related work; most (88%) were very or somewhat satisfied with this work, while 8% were somewhat or very dissatisfied. Nearly half had been tested for HIV; of these, 1 in 12 had tested positive.

**Family members and significant others** (N = 222): Of the 222 people who responded, more than half (56%) were female. However, females made up considerably more of the Halifax and Montreal samples (51 and 58%, respectively) than of the Toronto, Vancouver and CAS samples (38, 41 and 29%, respectively).

About three quarters (78%) chose English as their official language; one quarter (23%) chose French. Two thirds (66%) were working for pay. Consistent with the differential sex distribution (see below) and with their relatively greater ages, those in the Vancouver sample who were not working for pay (52%) were more numerous than was the case for the other cities and the CAS group (20 to 33%).

Their mean age (39 years) was nearly three years higher than that of the client group (36 years) and nearly a year higher than that of the caregiver group (38 years). This small difference in the mean ages is accounted for by the fact that only 16% of this group were parents; the largest number (44%) were lovers or spouses, 14% were siblings, 1% were children, 3% were other relatives and 22% were friends. (In the Vancouver sample the mean age, 43 years, of the family member and significant other group was considerably higher than for the other cities and the CAS sample; the Vancouver sample also contained the highest percentage (25%) of parents.)

As with the client and caregivers samples, the educational level of the family members and significant others was very high: only 1% had not completed high school and 78% had a university or college degree. Three quarters (78%) were born in Canada and 15% in the U.S.A., United Kingdom or Europe. (The country of origin of younger members of this sample - those 19 to 29 years of age - while in similar proportion regarding Canada (79%), was less heavily identified with the U.S.A., U.K. and Europe - only 10% - and more heavily identified with the Caribbean, Africa and Asia: 10% compared to 3% in the total sample.)

The vast majority (96%) of family members and significant others said they lived in urban environments. Although as many as 75% (the total of parents, spouses and lovers) conceivably could have answered that the person with HIV with whom they were associated was financially dependent on them, in fact, only 5% said that the person was completely dependent and only 31% said the person was partially dependent. Nevertheless, 80% of the respondents had daily contact with the infected person, suggesting that the dependency level for social, if not for financial, support was quite high.

Fifty-six percent of the family members and significant others who responded had been tested for HIV; however, the proportions ranged from a low of 35% in Halifax to a high of 73% in Toronto. Of the 68% who had been tested for HIV in Vancouver, 29% had tested positive (the highest rate in any sample); of the 56% who had been tested in Montreal, only 2% had tested positive. Those who had tested positive were concentrated in the 30-39 year age group within this sample; only 27% of this age group had not been tested, compared to approximately 50% of those in other age groups. Those in this age group were also more likely to have the HIV-positive person about whom they were concerned living with them (69%, compared to 47% of the other age groups).

## Limitations

Review of the responses indicated that there was some ambiguity in parts of the questionnaires. For example, all services apparently existed in all areas covered by the survey, so ***reported unavailability*** must have reflected either lack of awareness or inaccessibility. In another example, "adequate" was used to describe some of the services in the lists; this could lead to underreporting of the availability of that service even when it existed.

Some respondents checked off all of the services as "most needed" even when they reported only a few as being used. Further, in the caregiver survey, it was difficult to discern whether caregivers responded to their own needs or to the needs of their clients.

Finally, in an open-ended question, caregivers were asked to describe what they considered to be the special needs of the groups they served. Responses indicated that this question was not fully understood and therefore details about certain subgroups of clients are not available (for example, children with HIV, hemophiliacs, prisoners, and native people) from the caregivers' perspective.

## Data analysis

Approximately 200 frequency tables, relating demographic data to HIV status, problems related to mental health, and services (available, needed and used) were produced. The tables compare mental health problems and services availability and need, by city, by HIV status of the clients or cared-for persons, by age, years of HIV caregiving and so forth.

Some secondary analysis was performed which compared problems (grouped into several problem areas, such as information, behaviours, fears and concerns, practical problems), services, service needs and barriers to service among clients and several client subgroups, among family member and significant others, and among caregivers and several caregiver subgroups. A Psychological Distress scale was developed from the mental health problem list on the questionnaire.

Findings from these analyses are found throughout the text of this report. Further details may be obtained by writing directly to Dr. Donna Lamping, Department of Epidemiology and Biostatistics, McGill University, c/o Department of Medicine, Division of Clinical Epidemiology, The Montreal General Hospital, 1650 Cedar Avenue, Montreal, Quebec, H3G 1A4.

# Appendix II

## Mental Health and AIDS National Hearings

### Purpose

In early 1990, the Federal Centre for AIDS Working Group on HIV Infection and Mental Health commissioned a national series of hearings to supplement information gathered through its needs assessment. The purpose of the hearings was to give Canadians an opportunity to discuss their HIV and AIDS related mental health needs and to define ***innovative solutions*** to these needs.

### Methodology

The Mental Health and AIDS National Hearings consisted of four phases. The ***first phase*** (April to July 1990) was designed to:

- increase public awareness of the mandate of the Working Group on HIV Infection and Mental Health and to generate interest in the national hearings.
- reach Canadians affected by HIV/AIDS and facilitate the submission of written briefs which reflected the mental health needs of a wide range of individuals and groups.

The ***second phase*** (August to December 1990) involved examining the written briefs, and selecting respondents and helping them prepare oral presentations.

During the ***third phase*** (December 1990 to February 1991), Mental Health and AIDS National Hearings were conducted in Halifax, Montreal, Toronto and Vancouver.

The ***final phase*** (February to March 1991) involved analyzing and synthesizing the data and writing the final report.

### Data analysis

Data were gathered in several ways. Individuals and groups were encouraged to complete a written brief and needs chart, outlining:

- their mental health needs
- the solutions to these needs
- impediments to the suggested solutions
- ways around the impediments
- implications of the suggested solutions
- strategies for evaluation.

***Innovative solutions identified during the hearings***

- ***Community-based volunteer home care program***
- ***Conference calls for support and counselling in isolated areas***
- ***Separate unit for HIV+ prisoners***
- ***Staff exchange program between expert and non expert HIV care teams***
- ***Mental health caregivers network***
- ***Hospice based in a private home***
- ***Small town collaborative educational workshop for communities***
- ***Cooperative model for AIDS Coalitions***
- ***Community-based buddy system support***
- ***Community-based parents support group and network***

## About the groups submitting written briefs

Forty-three group questionnaires were completed and returned. Three of these were joint submissions while three groups submitted completed needs charts but did not complete the questionnaire. Two thirds (63%) of the 49 submissions received reflected a local perspective. The remaining third (36%) provided either a national focus or a provincial focus. Equal numbers of the submissions were AIDS-specific and not-AIDS-specific.

| SUBMITTING GROUP | No. | % |
|---|---|---|
| Community-based Organization | 23 | 48 |
| Health Department | 7 | 15 |
| Detention Centre | 5 | 10 |
| Health Care Institution | 5 | 10 |
| Therapist | 2 | 4 |
| Social Worker | 2 | 4 |
| Hotline | 1 | 2 |
| Hospice | 1 | 2 |
| Nurse | 1 | 2 |
| Family | 1 | 2 |

## Findings

Most respondents also completed a group characteristic questionnaire for the population represented in their submission. Letters of support and verbatim transcriptions for those groups that presented at the hearings also provided data about solutions.

- The **needs** most frequently stated in submitted briefs were for counselling and support, improved services in general, education and improved medical care.
- The most frequently suggested **solutions to meet these needs** were education and training, improved and increased number of resources, and support and counselling for those affected by HIV and AIDS. Lack of personnel and lack of funding were the most frequently stated **impediments to the suggested solutions**. Lack of recognition of the needs and resistance and reluctance to do anything were also identified, but to a lesser extent.
- Groups most frequently suggested education as a **way to get around the impediment**. Improving and increasing the number of resources, increased funding and support and counselling were indicated as ways of getting around the impediment, but to a lesser extent.
- Finally, the most frequently indicated **implications of the suggested solutions** were that the needs would be better met and the wellbeing of those affected by HIV or AIDS would be improved.

The three most frequently suggested solutions: support and counselling; improved and increased numbers of resources; and education and training were suggested by all regions of Canada in similar percentages.

The solution of support and counselling was most frequently suggested in small cities. Improved and increased numbers of resources and education and training were most frequently suggested in rural settings.

## Appendix III

## Caring Together / Entraide Conference for Caregivers

The number of people affected by HIV infection in Canada continues to increase, yet the number of persons who care for those infected with the virus is at risk due to fatigue and burnout. Caregivers who leave HIV or AIDS care may not be replaced. It was out of this major concern that Caring Together / Entraide was organized.

Conferences were held in Ottawa (March 9 to 11, 1990) and one week later in Calgary, Alberta. The theme was "to care for the caregiver" and the conferences were organized by a subcommittee of the Federal Centre for AIDS Working Group on HIV Infection and Mental Health, in collaboration with the Canadian AIDS Society and the Canadian Hemophilia Society and funded by the Federal Centre for AIDS, Health Protection Branch, Health and Welfare Canada. The subcommittee also consulted with the AIDS Committee of Toronto, the AIDS Committee of Ottawa, AIDS Calgary and many other individuals and groups across Canada.

Caring Together / Entraide was designed to:

- provide a national forum for the exchange and development of strategies directly affecting caregivers
- provide a constructive and practical resource for caregivers from many different disciplines and from many different regions of Canada
- provide a model for caregiver support and networking that would impact in a positive way on caregivers

Individuals from every province and territory of Canada were represented. Approximately 500 caregivers attended the Ottawa conference and 300 the one in Calgary. The three main problems participants identified were:

- high level job-related stress and frequent burnout
- occupational and personal stigma related to working with HIV-infected individuals
- lack of support systems, which leads to personal and professional isolation

At each conference, caregivers explored many issues affecting their lives in small workshops. They were asked to name the problems and find elements of solutions. Among the variety of solutions, caregivers noted that it was very important to maintain a balance in life, fullfilling physical, emotional, spiritual and social needs along with professional needs.

Throughout both conferences, it became evident that caregivers require strategic support systems if they are to continue working in the area of HIV care. While Caring Together / Entraide functioned as a resource for AIDS caregivers in Canada, these conferences also witnessed that no system exists in Canada which serves to provide resources and problem-solving strategies to AIDS

caregivers on any regular basis. Though we are entering into the second decade of the epidemic, many individuals reported that Caring Together / Entraide was their first opportunity to discuss significant issues with caregivers from other professions and from other job contexts. Caregivers found this experience mutually beneficial and supportive. There was also optimism that Caring Together / Entraide would be an annual event. Caregivers at the conferences made two main recommendations:

- A formal system of networking should be established for caregivers to address their ongoing needs and to develop resources.
- The caregiver conference should be repeated on a regular basis to provide caregivers with:
  - an opportunity to exchange ideas and information
  - strategies and practical skills for self-development and self-care (especially models for coping with stress and burnout)
  - a forum to develop and provide leadership in the field of HIV care

As a result of Caring Together / Entraide, a number of caregiver support groups have been formed across Canada, and networking among caregivers is continuing. The conference report was published in January 1991. Copies are available from the Federal Centre for AIDS, Health Protection Branch, Health and Welfare Canada, Ottawa, Ontario K1A 0L2

# Appendix IV

## A Model for HIV-Related Health Services

The services available to people living with HIV vary from province to province. One possible model was developed by the Ontario AIDS Advisory Committee, Subcommittee on Co-ordination of Services, and is reprinted here with permission.

The subcommittee describes the following chart as the natural history of HIV disease, and it lists the medical and mental health services that individuals with HIV may require at different stages of the illness. The subcommittee stressed that:

- although there is very little variation in the services involved at any stage of the disease, the intensity of use will vary.
- in addition to using these formal and informal health services, people living with HIV will turn to partners, families and friends for care and psychosocial support.

**Phase A**
**Pre-Test**

### I - No Informed Consent* or Diagnosis of HIV Infection Via Other Diagnosis

| Activity | Services | Comments |
|---|---|---|
| Testing for Insurance, Visa Requirements | Insurance Physician | Pre- and post-test counselling and informed consent are essential. |
| | Family Physician | Referrals to formal system should occur. |
| Other Physician/Dentist | Specialist<br>Dentist | HIV infection may be suspected and referral to formal system will occur. |

### II - Informed Consent - Pre-Test Counselling

| Activity | Services | Comments |
|---|---|---|
| Pre-test Counselling | Family Physician<br>STD Clinic<br>Community-based Organization<br>Public Health Units<br>HIV Outpatient Clinic | Referral to test facilities possible. |
| | Red Cross Blood Donor Clinic | All donated blood is screened for HIV. Referral if positive result. |
| Medical Assessment | Family Physician<br>STD Clinic<br>HIV Outpatient Clinic | |

**Testing without informed consent is ethically and legally unacceptable. However, it does sometimes occur and, in that situation, positive test results can be more devastating. In addition, individuals may be suspected of being HIV positive as a result of other conditions (eg. dermatologist diagnosing Kaposi's sarcoma).*

**Phase B Testing**

**I - Negative Results**

| Activity | Services | Comments |
|---|---|---|
| Post-test Counselling | Family Physician<br>STD Clinic<br>HIV Outpatient Clinic | Although individuals who test negative formally drop out of the system, they may be seen on an ongoing basis if their behaviour or perception of risk does not change. |
| Referral | Community-based<br>AIDS Organization<br>Other Counselling | |

**II - Positive Results**

| Activity | Services | Comments |
|---|---|---|
| Medical Care | Family Physician<br>HIV Outpatient Clinic | Monitor individual (three month appointments) |
| Post-test Counselling (Short-term) | HIV Outpatient Clinic<br>Public Health<br>Family Physician<br>STD Clinic<br>Community-based<br>AIDS Organization | Individuals may need a referral for long-term ongoing counselling |

**Phase C Asymptomatic HIV Disease**

**I - No Laboratory Abnormalities/ Laboratory Abnormalities (common services)**

| Activity | Services | Comments |
|---|---|---|
| Medical Care | HIV Outpatient Clinic<br>Family Physician<br>Dentist | Without laboratory abnormalities, medical care consists of monitoring the individual |
| Counselling (Long-term) | HIV Outpatient Clinic<br>Community-based<br>AIDS Organization<br>Private Therapist | Prior to developing laboratory abnormalities, counselling may occur on an ad hoc basis |
| Other | Housing Services<br>Income Maintenance<br>Legal Services | |

**II - Laboratory Abnormalities**

| Activity | Services | Comments |
|---|---|---|
| Medical Care | HIV Outpatient Clinic<br>Family Physician<br>Dentist | HIV-related early intervention may begin. Disease specific treatments may be required. |
| Counselling | HIV Outpatient Clinic<br>Community-based<br>AIDS Organization<br>Private Therapist | If the individual is not receiving counselling it may be required. If the individual is receiving counselling, it will likely become more intense. |
| Other | Housing Services<br>Income Maintenance<br>Legal Service | Referrals are more likely to occur. |

| | Activity | Services | Comments |
|---|---|---|---|
| **Phase D Symptomatic HIV Disease /Recovery** | Medical Care | HIV Outpatient Clinic<br>Hospital<br>Family Physician<br>Dentist<br>Home Care | Medical care consists of late intervention treatments. |
| | Counselling | HIV Outpatient Clinic<br>Community-based AIDS Organization<br>Private Therapist<br>Pastoral Care | |
| | Other | Housing Services<br>Home Care<br>Homemaker/Meals on Wheels<br>Income Maintenance<br>Legal Service<br>Funeral Home | |
| | **Activity** | **Services** | **Comments** |
| **Phase E Palliation** | Medical Care | Inpatient Hospital<br>HIV Outpatient Clinic<br>Dentist<br>Hospice<br>Home Care<br>Family Physician | Palliative care not active care. May involve primary prophylactic care. Hospice care may be general or HIV-specific. |
| | Counselling | HIV Outpatient Clinic<br>Community-based Organization<br>Private Therapist<br>Pastoral Care<br>Funeral Home<br>Hospice<br>Inpatient Hospital<br>Religious Institution | |
| | Other | Housing Services<br>Income Maintenance<br>Legal Services<br>Funeral Home | |
| | **Activity** | **Services** | **Comments** |
| **Phase F Bereavement** | Counselling | HIV Outpatient Clinic<br>Community-based AIDS Organization<br>Private Therapist<br>Pastoral Care<br>Funeral Home<br>Hospice<br>Bereavement Organization | |